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Missouri Head Injury Advisory Council

FY 89 Annual Report & *Action Plan* for Services



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Missouri Office of Administration

FY 89 Annual Report & *Action Plan* for Services



**John Ashcroft, Governor
State of Missouri**

**James R. Moody, Commissioner
Missouri Office of Administration**

**Stan Perovich, Director
Division of General Services**

**Judith A. Ferguson, Chairman
Missouri Head Injury Advisory Council**

**Susan L. Vaughn, Director
Missouri Head Injury Advisory Council**

**Missouri Head Injury Advisory Council
Division of General Services
Office of Administration
Post Office Box 809
Jefferson City, Missouri 65102**

Preface

Referred to as the "silent epidemic", head injury has been cited nationally as the leading cause of death and disability up to the age of 44. In Missouri, hospitals reported over 6,500 head and spinal cord injuries to the Missouri Department of Health during the 1988 calendar year. The head and spinal cord injuries are overrepresented primarily among 15-24 year old individuals, and to a lesser extent, young children and older adults.

This overrepresentation is directly related to the causes of head and spinal cord injuries as over half of the injuries are caused by incidents related to motor vehicles, bicycles, motorcycles, and off-road vehicles. Falls account for nearly one-third of the injuries reported in Missouri and are the second leading cause. Other causes include diving and other recreational accidents, industrial accidents, assaults and weapons.

Emergency medical and technologic advances have resulted in greater survival rates for persons who have sustained a traumatic head injury. The number of survivors will continue to increase as emergency medical services and hospital care, including trauma centers, continue to improve and become more readily available. The increased number of survivors has placed greater demands for rehabilitation services, long-term care, supervised residential living, vocational rehabilitation, employment, and community support programs. Many of these services are available to other disability populations, however, the services are either difficult to access or not readily available to persons with head injuries.

The policy makers in Missouri have recognized the problems associated with head injury and have put forth several efforts to address the issues. One of the strategies for addressing the issues was the creation of the Missouri Head Injury Advisory Council, created in 1985 to study the unique rehabilitative and service needs of survivors of head injury and their families.

Organizationally, it is assigned to the Missouri Office of Administration, and shall:

- (1) Promote meetings and programs for the discussion of reducing the debilitating effects of head injuries and disseminate information in cooperation with any other department, agency or entity on the prevention, evaluation, care, treatment and rehabilitation of persons affected by head injuries;
- (2) Study and review current prevention, evaluation, care, treatment and rehabilitation technologies and recommend appropriate preparation, training, retraining and distribution of manpower and resources in the provision of services to head injured persons through private and public residential facilities, day programs and other specialized services;
- (3) Recommend what specific methods, means and procedures should be adopted to improve and upgrade the state's service delivery system for head injured citizens of this state;
- (4) Participate in developing and disseminating criteria and standards which may be required for future funding or licensing of facilities, day programs and other specialized services for head injured persons in this state; and
- (5) Report annually to the commissioner of administration, the governor, and the general assembly on its activities, and on the results of its studies and the recommendations of the council.

In keeping with the legislative mandate, this report is organized into two major chapters: (1) Description of Service Model & Needs and (2) Action Plan Update. In Chapter One, an attempt is made to describe a model service system, including prevention strategies, and existing services in the state. The inclusion of known providers should not be interpreted as an endorsement of those particular services, but as an attempt to describe the current service delivery system. It is possible that services are being provided by other agencies which the council is unaware of and, thus, not included in that section.

Chapter Two outlines goals and objectives for developing and implementing a service delivery system as envisioned by the council.

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Introduction

Creation of Council

During the summer of 1984, a Joint Interim Committee on Head Injury established by the Missouri General Assembly held several hearings around the state. The committee made recommendations including the creation of an advisory council to continue studying the needs of persons with head injury and their families. The Missouri Head Injury Advisory Council was subsequently established under an Executive Order March 5, 1985, by Governor John Ashcroft, who also appointed 21 of the 25 members.

The other four members represent the Missouri General Assembly: two are senators appointed by the Senate President Pro Tempore and two are representatives appointed by the Speaker of the House of Representatives. The 21 members represent parents, consumers, professional, and state agencies representing education, mental health, health, public safety, medical services, vocational rehabilitation, insurance, and vocational education.

The council is administratively assigned to the Mis-

souri Office of Administration, Division of General Services.

Legislative Authority

In 1986, legislation was enacted which established a head and spinal cord injury registry and established the Missouri Head Injury Advisory Council statutorily. The council is to make recommendations to the governor for developing and administering a state plan to provide services for Missourians with head injury and their families.

In keeping with the council's bylaws, the Missouri Head Injury Advisory Council held five meetings during Fiscal Year 1989. At its September meeting the council re-elected Judith Ferguson as chairman and Representative Sheila Lumpe as vice-chairman.

This report provides an update of the council's progress in meeting its goals and objectives of which have been defined to meet the major goal of recommending a statewide service delivery system for survivors of head injury and their families.

Definition of Head Injury

"Head injury" or "traumatic head injury" is defined as: "a sudden insult or damage to the brain or its coverings, not of a degenerative nature. Such insult or damage may produce an altered state of consciousness and may result in a decrease of one or more of the following: mental, cognitive, behavioral or physical functioning resulting in partial or total disability. Cerebral vascular accidents, aneurisms and congenital deficits are specifically excluded from this definition" (Section 192.735 RSMo).

Head injury or brain injury is a traumatic insult to the brain requiring extensive services over an extended period of time. Although the injury is not always visible, it may cause physical, emotional, intellectual, social and vocational changes. There are two types of head injury: closed head injury and open head injury. A "closed head injury" refers to damage that occurs within the skull after a blow to the head. Although the skull may stop on impact, the brain will often continue to whip back and forth against the

skull from within causing damage. The second category of head injury referred to as "open head injury" is a visible assault and may be the result of a gun shot wound or an accident.

The symptoms of head injury may vary greatly, depending on the extent and location of the injury. The following are three types of impairments associated with head injury. Any or all of the impairments may occur in varying degrees and there may be other symptoms than those listed below:

- *Physical impairments*; including speech, vision, hearing and other sensory impairments; headaches, lack of coordination; spasticity of muscles, paralysis of one or both sides and seizure disorders. Although many survivors of head injury may appear to be recovered physically, they may still have problems with visual perception or fine motor control.
- *Cognitive impairments*; which may result in memory deficits, either long or short term; and

problems with concentration, attention, perception, communication, reading, writing, planning, sequencing or judgment. Learning problems which have been identified include decreased ability for abstraction less initiative and distractibility.

•*Psycho-Social-Behavior-Emotional impairments;* including fatigue, mood swings, denial, self-centered, anxiety, depression, lowered esteem, sexual dysfunction, restlessness, lack

of motivation, inability to self-monitor, difficulty with emotional control, inability to cope, agitation, excessive laughing or crying or difficulty relating to others. Personality can be altered and the person may become argumentative or become socially withdrawn and unable to interact with peers.

Often a person with a head injury will insist he or she can understand completely, when in actuality is totally confused.

"Minor" Head Injury

Traumatic head injury or brain injury may produce a range of severity from bumps or bruises to instant death. As with other disabilities, head injury is usually categorized as mild/minor, moderate or severe. Depending upon which areas of the brain are injured and the extent of injury, head injuries may lead to death, coma, or long-lasting disabilities.

The Federal Interagency Head Injury Task Force Report released in June 1989, provides specific recommendations with regard to minor head injury. The report explains:

In so-called minor head injury or cerebral concussion, there is brief or undetected loss of consciousness and no recognizable major acute complications. However, the lack of overt symptoms may prove deceptive. Permanent structural brain damage has been documented after minor concussion in laboratory experiments. Further, brain imaging technologies, including magnetic resonance imaging (MRI) and positron emission tomography (PET), have revealed structural and metabolic changes in humans after concussion. These changes correlate with documented neurobehavioral changes after even extremely minor head injury without loss of consciousness. Owing in part to the studies, the "post-concussion syndrome" is increasingly being recognized by clinicians as resulting primarily from organic brain damage. The failure to diagnose this syndrome and to institute management is likely to prolong the resulting incapacitation and complicate subsequent treatment. Given the fact that the annual incidence of minor head injury is **extraordinarily** high (approximately 1.5 million each year), the social and economic impact is considerable. Significantly, minor head injury can lead to a permanent deficit of brain function; repeated minor head injuries often do cause permanent brain damage.

There is growing body of evidence that repeated TBI regularly suffered in certain **sports**, particularly observed in boxing and football, poses not only an acute risk to the athlete, but may also result in long-term organic brain damage. This includes learning disabilities in children and premature dementia in adults. The popularity of a given sport should not interfere with an effort to develop new or improved protective equipment and to explore changes in rules or regulations that will diminish the probability of TBI (traumatic brain injury).

The Task Force Report recommends the following :

- Define anatomic, physiologic and behavioral criteria for measuring the severity of minor head injury.
- Encourage academic and professional institutions to include in primary and continuing education programs for health care providers the recognition and management of minor head injuries. Encourage the inclusion of minor head injury management in community-based TBI educational programs.
- Stimulated high-risk industries and union groups to establish model acute and subacute management programs for workers recovering from minor head injury.
- Develop early follow-up and intervention programs for patients and family members that emphasize maintenance of established role relationships and dynamics of family adjustment.
- Create in-service training programs for educators and counselors designed to make them aware that minor head injuries can result in behavioral changes and learning difficulties which interfere with the activities of daily living.
- Increase the support for research on minor head injury, particularly in athletics.

Chapter One:

DESCRIPTION of SERVICE MODEL & NEEDS

Head Injury Incidence/Prevalence

Determining the number of persons with head injury in Missouri who have service and program needs has been a priority for the Missouri Head Injury Advisory Council. In order to plan for services, the council needs to know not only the type of services, but how many people will need the various programs. From the time the council was created this information has been difficult to determine due, in part, to (1) the lack of prevalence studies and (2) omission of head injury in reporting systems. To address this problem the council initiated two projects.

The first priority was to initiate legislation mandating hospitals to report head injuries to the Missouri Department of Health, Division of Health Resources, the agency responsible for gathering and managing public health statistics. The legislation was introduced and passed in 1986 and requires the reporting of head and spinal cord injuries to the department. The Division of Health Resources implemented the head and spinal cord injury registry July 1, 1987, and has analyzed the data obtained during the 1988 calendar year. Some of the data is contained in this report.

The second project initiated was a statewide random telephone poll to determine: (1) how knowledgeable are Missourians with regard to head injury and (2) how prevalent is head injury in Missouri.

Incidence

In the past, the council has relied on national statistics to project how many head injuries occur each year. Through the Missouri Head and Spinal Cord Injury, Missouri will have statistics reflecting injuries in Missouri. The register collects information from the scene of the accident until hospital discharge. The registry not only allows the state to collect information with regard to number of injuries, cause of injury, and severity of injury, but also provides a mechanism for evaluating emergency medical services system. The Department through contracts with the National Highway Traffic Safety Administration is in the process of linking five computerized data files, which will allow the state to better study the cause and effect of injuries in Missouri. The department will also study costs associated with injury, including cost of rehabilitation and other services following discharge from the hospital.

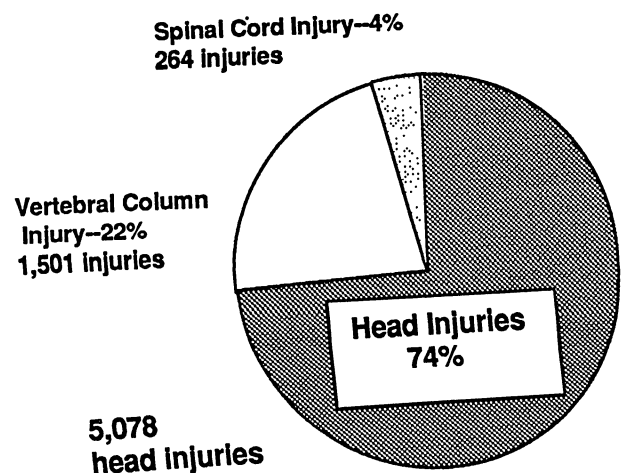
Missouri Head and Spinal Cord Injury Registry

The Department of Health has released figures regarding the data received during the first calendar year since implementation of the registry. The department has grouped head and spinal cord injuries into three groups—head injuries, spinal column injuries, and spinal cord injuries.

In 1988, 5,078 persons with head injuries were reported, 1,501 with spinal column injuries, and 264 as spinal cord injuries. The department shows the number of deaths related to head and spinal cord injuries as 407.

Age at the Time of Injury

The registry data shows that head and spinal cord injuries are overrepresented primarily among 15-24

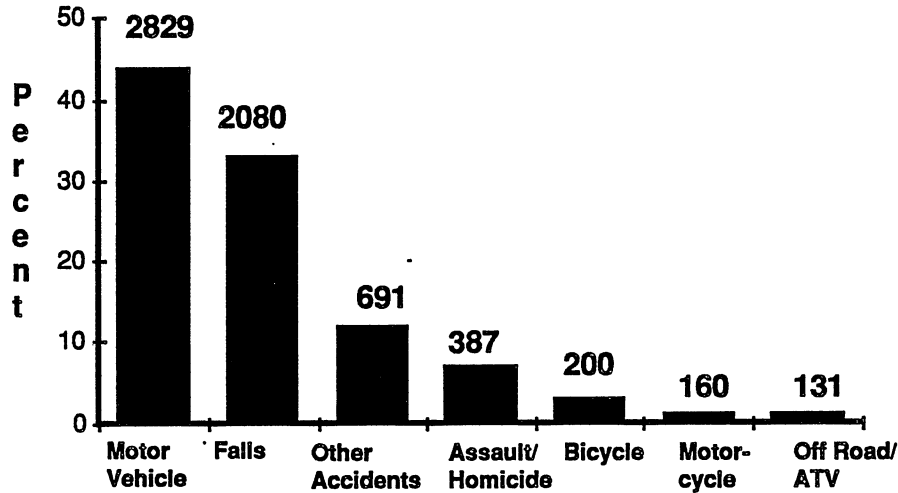


Causes of Head and Spinal Cord Injuries

1988

children and older adults. This overrepresentation is directly related to the causes of the injuries. Over half of the injuries are caused by incidents related to

motor vehicles, bicycles, motorcycles, and off-road-vehicles. Approximately 55 percent of these causes occur among persons aged 15-34, a group that represents 39 percent of all injuries.

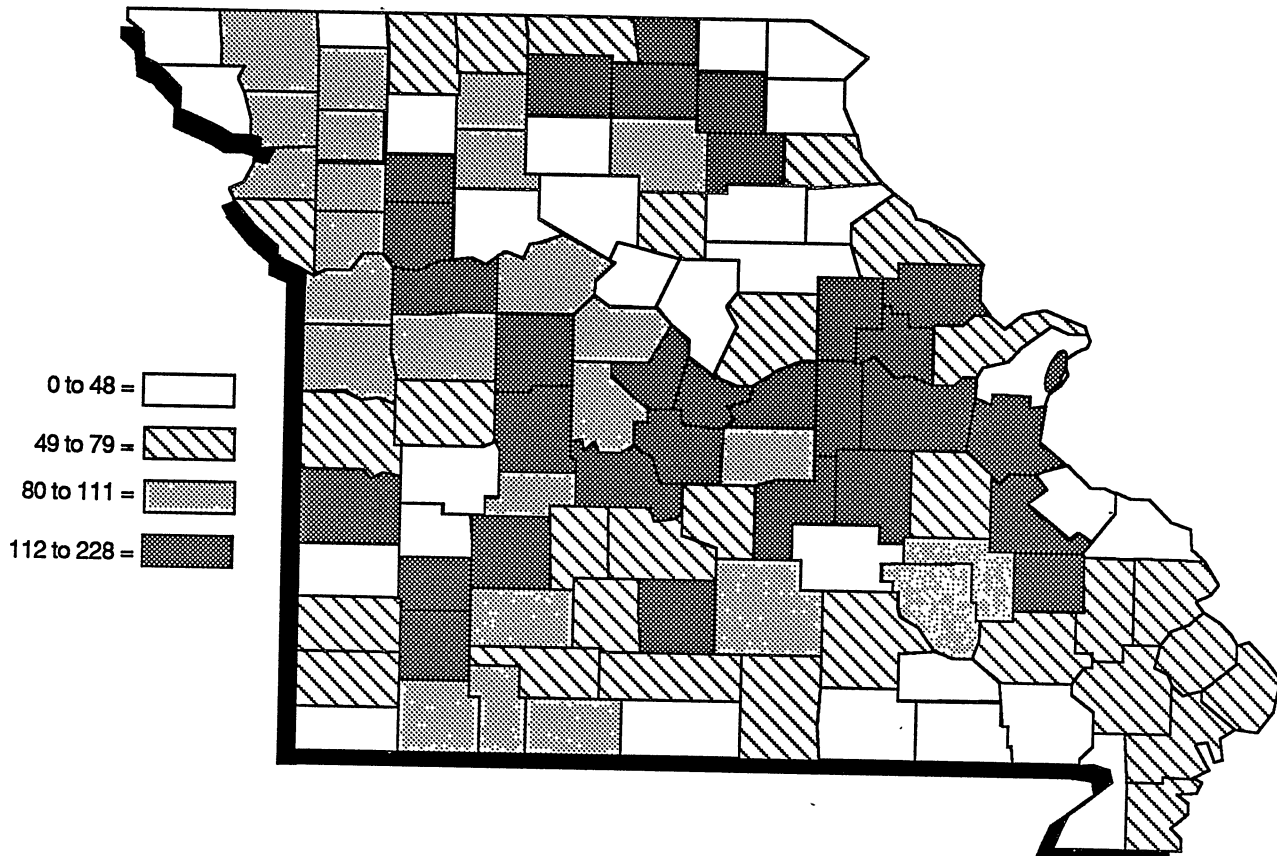


Falls account for nearly one-third of head and spinal cord injuries and are the second leading cause of these injuries. Thirty-seven percent of the head and spinal cord injuries caused by falls occur among persons age 65+ (compared to 16 percent of all head and spinal cord injuries), and another 28 percent of head and spinal cord injuries due to falls occur among children less than age 15.

Head Injuries by County of Injury

Rate per 100,000

1988



tional Rehabilitation.

Vocational Rehabilitation readies a person for employment. The federal Rehabilitation Act of 1975 as amended is administered through the Missouri Department of Elementary and Secondary Education, Division of Vocational Rehabilitation. Vocational Rehabilitation is a program designed to help physically or mentally disabled persons become employable. Many services are provided under the federal program of which some are free and others assessed by the ability to pay. Some of the services made available to clients are as follows:

- 1.) A doctor's examination to assess the severity of the disability.
- 2.) Medical and hospital care to reduce the disability and improve chances for employment.
- 3.) The purchase of such items as artificial arms and legs, braces, wheelchairs or hearing aids to increase the ability to work.
- 4.) Job training. This may include college education, commercial or trade school, or on-the-job training.
- 5.) Work evaluation and adjustment.
- 6.) Transportation allowance while receiving medical treatment or job training arranged by the vocational rehabilitation counselor.
- 7.) An allowance sufficient for noon meals if job training is provided in the client's home community.
- 8.) The cost of room and board if job training is provided in the client's home community.
- 9.) Equipment needed for employment (including tools and a license if needed).
- 10.) Help in finding a job.
- 11.) Help in solving problems encountered on the job.

To be eligible for services through the Division of Vocational Rehabilitation a person must meet the following requirements:

- 1.) The presence of a physical or mental disability which for the individual constitutes or results in a substantial handicap to employment and
- 2.) A reasonable expectation that vocational rehabilitation services may benefit the individual in terms of employability.

Employment

Supported Employment refers to competitive employment occurring in integrated work settings and being performed by individuals with handicaps for whom either competitive employment has traditionally occurred or competitive employment has

been interrupted or become intermittent as the result of a severe disability and which, because of their handicaps, need ongoing job coaching, psychosocial and other support services to perform such work.

Sheltered Workshop Employment refers to an occupation-oriented facility operated by a not-for-profit corporation, which, except for its staff, employs only persons with a handicap and has a minimum enrollment of at least fifteen employable handicapped persons (Section 178.900 RSMo.). To be eligible persons must be certified by the Division of Vocational Rehabilitation.

Day Programs maintain the intellectual, emotional, social, vocational, and physical capacity of a person who may have received services from an acute rehabilitation, functional living rehabilitation and/or transitional living program, and is unable to maintain a job or participate in a vocational or educational program.

Residential Services

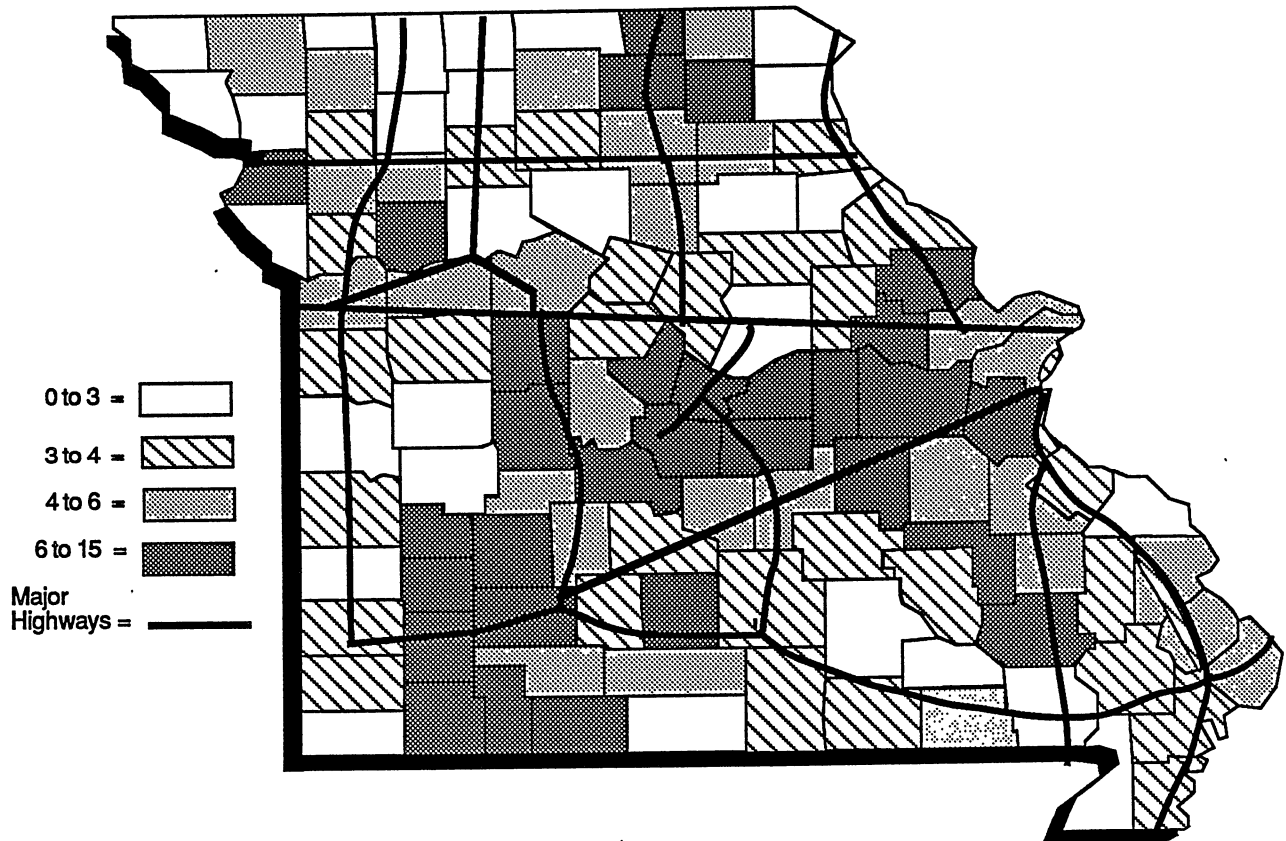
Ideally, a person suffering from a head injury would return to his/her natural environment following medical and rehabilitation care whether that be to live with a spouse, other family member(s) or independently/semi-independently. For those who are unable to return to his/her natural environment independently, then some type of housing or support which provides supervision and protection may be needed. Others may require continued rehabilitation, medical, or specialized care provided in a residential setting.

Home health care agencies provide three types of services: (1) In-home visits by nurses, which generally are covered by Medicaid or Medicare; (2) homemaker program providing non-medical assistance, such as grocery shopping, to elderly or handicapped persons who would otherwise be in nursing homes, which is a Medicaid service; and private duty (8 hours at a time), which is generally covered by private pay, insurance and sometimes Medicaid.

Personal Care Assistance provides in-home assistance which may include help with dressing, bathing, eating or other personal care activities, thus enabling a person to reside in a semi-independent living situation.

Independent Living Centers may provide counseling and/or supervision on a periodic basis, thus

Rate of Injuries Caused by Motor Vehicles Per Hundred Million Vehicle Miles 1988



The state map above shows the rate of head injuries caused by motor vehicles. According to the registry data, there are two predominate geographic clusters of motor vehicle head injuries in the state. One cluster is formed by the counties in central and eastern Missouri. The Department of Health explains that this cluster is likely due to two separate phenomena. Most of the counties surrounding the St. Louis metropolitan area have high motor vehicle head and spinal cord injury rates. This is one of the fastest growing areas of the state, as people are choosing to live in the suburban fringe rather than in St. Louis City or County. Even after adjusting for the high commuter mileage in these areas, there is an excess of head and spinal cord injuries in the St. Louis suburban fringe counties.

The group of counties with high injury rates in Central Missouri represents the second phenomenon: high injury rates in retirement and tourist areas close to the Ozark and Truman lakes in Central Missouri.

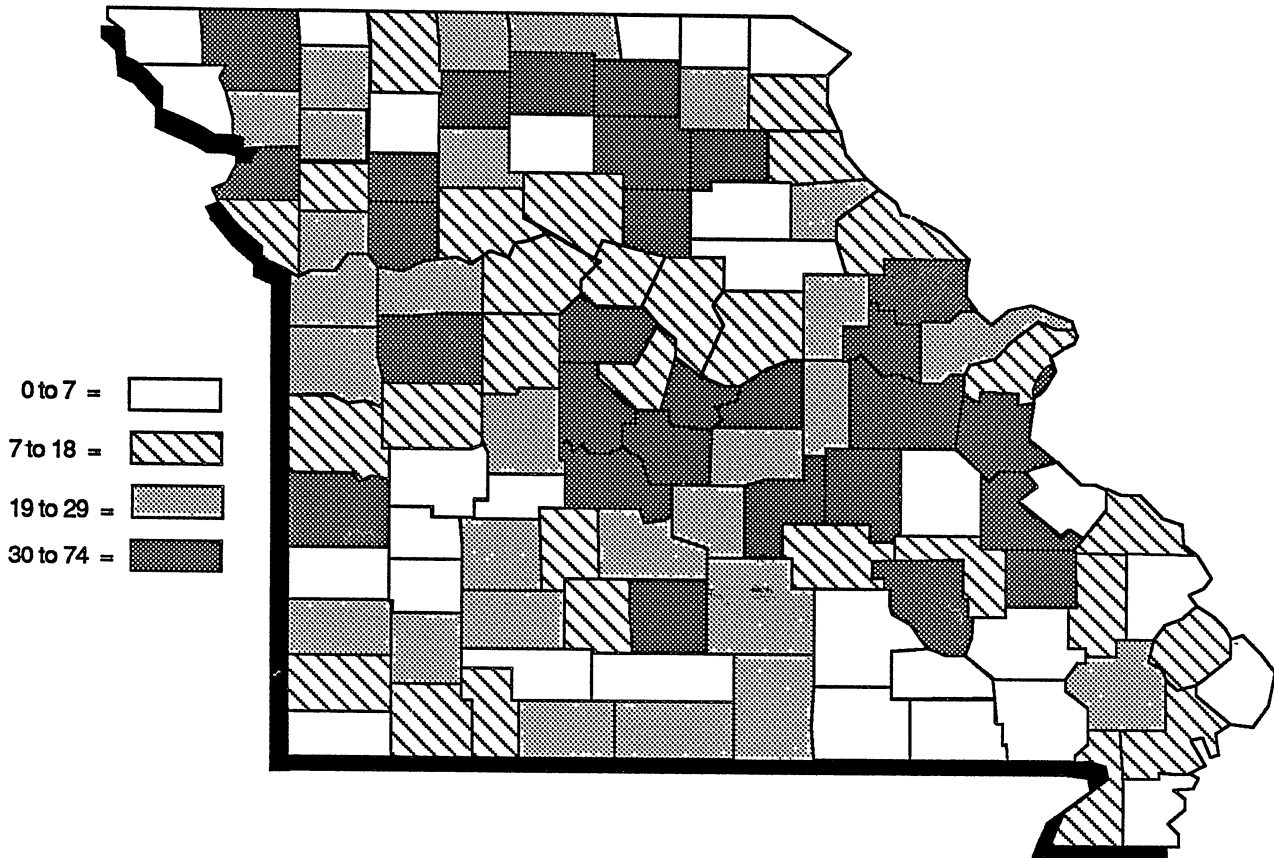
The second cluster of injury rates, located in Southwestern Missouri, also appears to be related to the tourist and retirement community. These counties include tourist attractions and retirement areas associated with Pomme de Terre, Stockton, Table Rock, and Taneycomo Lakes. These are among the fastest growing areas of the state.

As the map shows, there tend to be lower rates of motor vehicle-related head injuries on dual lane roads where travel is presumably safer. Generally, the injury rates are lower for the counties along the interstates from Kansas City to St. Louis, Omaha, Des Moines, and Joplin. The counties along the interstate from St. Louis to Cape Girardeau also have lower injury rates.

Eight percent of head and spinal cord injuries resulted in immediate death. There are few other medical conditions that have such a high immediate

Head Injuries from Falls

Rate per 100,000
1988

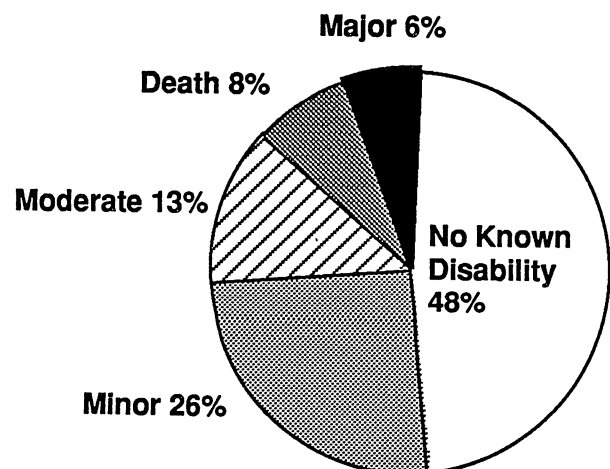


fatality rate. About 5 percent (290) had a major disability and were left in a vegetative state or needed the assistance of another person to perform daily living activities. Thirteen percent (677 persons) had a moderate disability and could no longer perform some previous activities by reason of either physical or mental deficit.

About three-fourths of the persons with a head and spinal cord injury had either a minor or no known disability upon discharge from the hospital. This figure may be misleadingly low in that followup studies in other states indicate that deficits from a head and/or spinal cord injury are often not detected until months after the incident.

(Note: The disability figures are based upon 84 percent of registry forms which had disability level indicated.)

Reported Level of Disability at Discharge 1988



Prevalence

By way of a contract with the University of Missouri Media Research, a total of 1,123 Missouri residents, 18 years of age or older, were interviewed by telephone between July 11 and August 11, 1988. The state was divided into seven regions which geographically represented the entire state. The largest proportions of the sample were St. Louis (31 percent) and Kansas City (21 percent) which reflects Missouri's population distribution.

The head injury survey questions pertained to three general areas: (1) Generally knowledge about head injury, its causes, and resulting problems; (2) extent of head injury, problems associated with head injury,

services received, and services needed, and (3) demographics. With regard to prevalence persons interviewed were asked:

• *Have you personally had a blow to the head which affected your ability to perform routine activities or work?*

• *Has any member of your immediate family had a blow to the head which affected his/her ability to perform routine activities or work?*

• *Do you personally know any Missouri residents who, within the last ten years, has had a blow to the head which affected his or her ability to perform routine activities or work?*

Statewide Head Injury Poll

Personally Experienced a Head Injury

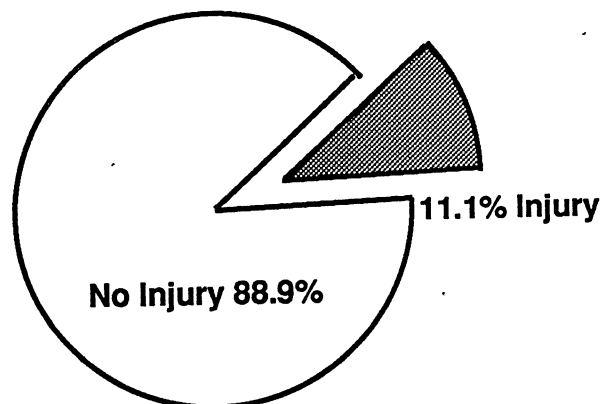
Eleven percent of those surveyed (125 persons) said they had personally experienced a head injury. Of these, 62 percent were injured seriously enough to lose consciousness. Most lost consciousness for only a few minutes, but 17 percent were unconscious for one to three hours, 7 percent were unconscious for four to 24 hours, while 5 percent were unconscious for an extended period of time.

Age at the Time of Injury

Eighty percent were below the age of 35 when they were injured. In fact, 23 percent were 12 or below and 22 percent were between 13 and 17. Sixteen percent were between 18 and 24, and 19 percent were 25 to 34.

Problems Associated with Head Injury

Seventy-six percent of those injured said they experienced headaches, and almost 57 percent said they developed problems with movement or balance. Twelve percent said they developed speech problems, and 10 percent said they experienced behavioral problems. Thirteen percent said they underwent personality changes, and 11 percent experienced impulsiveness. Fifteen percent of those injured said they had been unable to work or go to school continuously for more than six months since their injury.

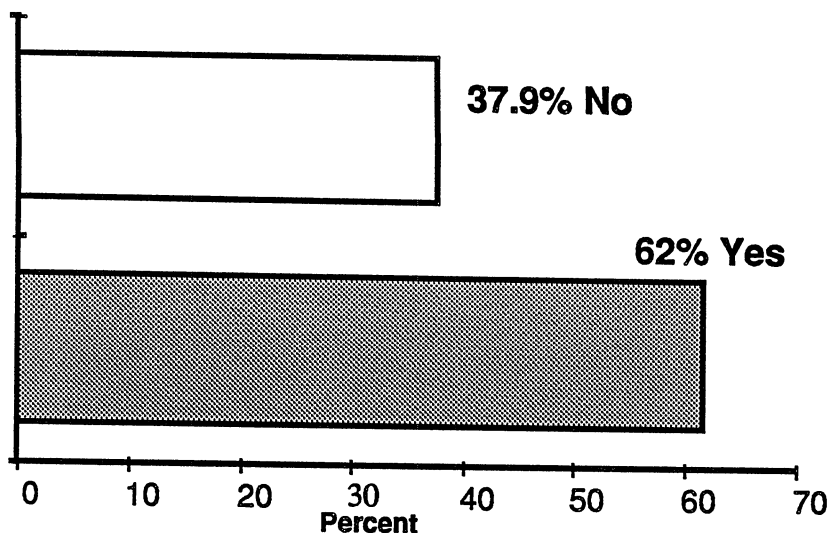


When asked, "Have you personally had a blow to the head which affected your ability to perform routine activities or work?", 11.1% answered yes.

Cause of Injuries

About 5 percent of those suffering injuries said they were involved in a car crash, while 3 percent had a fall. Slightly more than 1 percent were injured in an industrial accident. Others were injured by being hit or abused, while on a motorcycle or three-wheeler, while playing sports, while riding a bicycle or in a home or school injury of some type. All of those who said their injuries were the result of being hit or abused were below the age of 34.

Did you lose consciousness?



When those who had experienced a head injury were asked if they were unconscious, 62 percent answered yes. Most (71%) lost consciousness for only a few minutes, but 17 percent were unconscious for one to three hours, 7 percent were unconscious for for to 24 hour and 5 percent were unconscious for an extended period of time.

Family Member with a Head Injury

Almost 12 percent of those interviewed said that a member of his immediate family had received a head injury. Of those injured, 75 percent were male household members. Forty-six percent said that his son had been the person injured, while less than 10 percent said his daughter had been injured.

Sixty-eight percent said the injured family member had lost consciousness. Most were unconscious for longer periods of time than those who said they themselves had received a head injury.

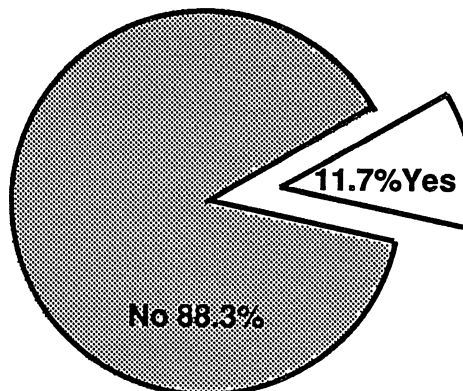
Almost 26 percent said the family member had not been able to work or go to school continuously for six months since the injury. Fourteen percent were unable to function on their own.

Services Required

Eighty-eight percent required the care of a physician, and 71 percent required hospitalization. Twenty-seven percent needed rehabilitation, and 15 percent said the family member required psychiatric care or counseling. Seven percent said the family member needed job training, while 8 percent said the family member needed nursing home care.

Nearly 10 percent reported that the family member's medical costs were \$50,000 or more.

When asked, "Has any member of your immediate family had a blow to the head which affected his/her ability to perform routine activities or work?", almost 12 percent answered yes.



Cause of Injury

Five percent were injured in a car accident and four percent were injured in a fall. A few were injured in motorcycle, three-wheeler accidents, diving or swimming accidents, in an industrial accident or while playing sports. Some were hit or abused or were shot.

Knows Someone with a Head Injury

Fourteen percent of those surveyed (160 persons) said they knew at least one person who had received a head injury. Sixty-three percent could recall one victim, while 20 percent could recall two, 9 percent could recall three and 4 percent could recall four. Four percent knew five or more persons. Of those who knew a person with a head injury, 81 percent said the person was a male.

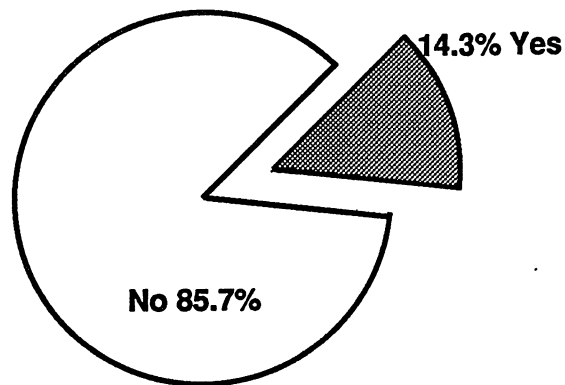
Problems Associated with Head Injury

Those interviewed reported a variety of effects as a result of the injury to their friends or acquaintances. Sixty-five percent said the person with the head injury had problems with movement or balance, 64 percent mentioned memory loss and 52 percent mentioned headaches. Forty-six percent reported speech problems, 15 percent developed seizures. Thirty-four percent said the person experienced personality changes, 32 percent became impulsive and 30 percent developed behavior problems according to those interviewed.

Cause of Injuries

Seven percent said the person(s) they knew was

Fourteen percent of those surveyed knew at least one who received a head injury.



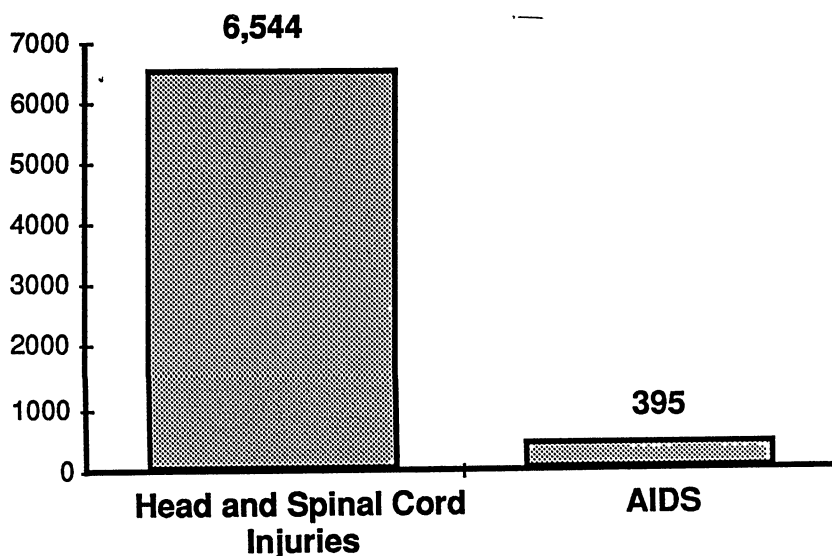
injured in a car accident. About 2 percent said the victim fell. A few were hit or abused, were injured in a motorcycle, three wheeler or bicycle accident, were injured while swimming or diving or were shot. Sports injuries, use of drugs or alcohol, industrial accidents and other types of accidents were mentioned.

Summary

Both the survey and the register indicate that head injuries are a serious public health problem in terms of number of cases, number of severely disabled persons, and number of deaths. The fact they occur primarily among young people makes the problem even more alarming. At the very least, those receiving head injuries reported experience headaches. Others are left with severe disabilities that render them incapable of working or even getting along with other people.

Those most at risk for head injuries are children and young adults. Males are more at risk than females. A second group at risk appears to be the elderly, who are more likely to be injured in a fall.

AIDs vs Head and Spinal Cord Injuries 1988*



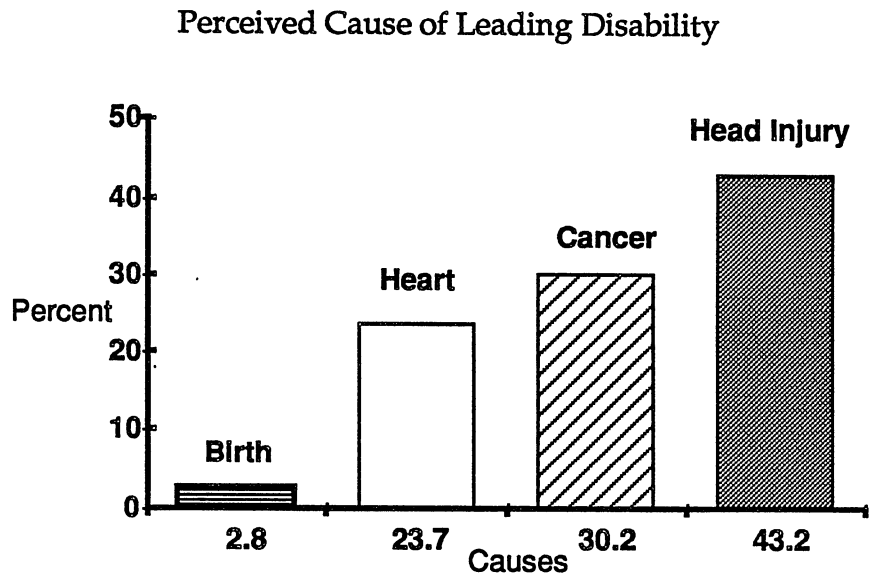
*Provided by the Missouri Department of Health

Public Knowledge of Head Injury

Forty-three percent of those interviewed said they thought injuries were the leading causes of death and disability among Missourians. Thirty percent thought cancer was the leading cause, while 24 percent thought heart disease was the leading cause. Less than 3 percent thought birth defects were major causes. Seventy percent said they heard a doctor or someone else use the term, "head injury."

Forty-two percent considered head injuries to be a very serious health problem, while 45 percent considered it a somewhat serious health problem.

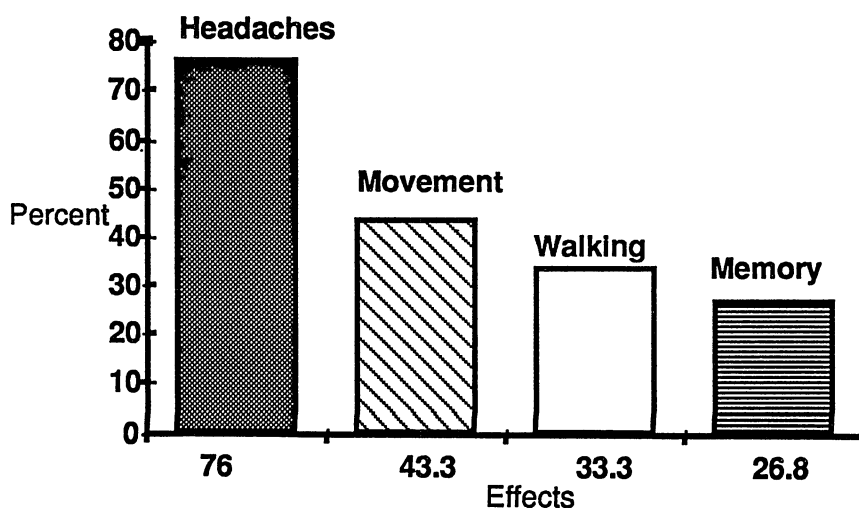
Seventy-five percent said car accidents most often accounted



for head injuries suffered by those living in Missouri. Falling was considered a major cause by 25 percent. Motorcycle or

three-wheeler accidents were mentioned by 11 percent. Almost 4 percent mentioned hitting or abuse as a cause.

Perceived Major Effects of Head Injury



Those interviewed were asked what types of problems they thought a person would have as a result of a head injury. Thirty-two percent mentioned paralysis, 29 percent mentioned memory loss, 16 percent mentioned thinking problems and 12 percent mentioned problems with walking.

Also mentioned were speech and learning problems and trouble with getting along with other people. A variety of problems were mentioned by a few of those surveyed. These included: eye problems or blindness, blood cots, fever, depression, brain damage, dizziness, headaches, cancer, epilepsy, deafness, coma and back pain.

Description of Service Model: Array of Services

The Missouri Head Injury Advisory Council has defined a service delivery system model addressing all of the service components including: **Prevention, emergency medical and medical services, rehabilitation, case management, residential, and community support services.** The council has defined services and organized them into the above categories which are similar to both the medical/health care community and the mental retardation/developmental disabilities community.

The Missouri Head Injury Advisory Council recognizes that the course of rehabilitation will vary according to the patient's needs and the availability of services. Part of the challenge of providing adequate care for persons who sustain traumatic head injury is the diversity of needs after injury. Post-injury needs can range from full time care to community re-integration. The order in which services are used can also vary; some people will move from acute medical care into community integration while others may require extended periods of nursing care. Thus, services must be flexible, but also allow for the most frequent progressions.

The service delivery system envisioned by the council is flexible. Rehabilitation of persons who have sustained traumatic head injury is based upon small steps emphasizing increased demands until the person's maximum level of independence is established. While returning to the community living is the

ultimate goal, however, it must be recognized that the level of functioning will vary and survivors of head injury may require differing support services.

Some of these services are in place and are provided by some state and local agencies. There are very few services and programs following acute or post acute (functional living) rehabilitation for persons who require long-term care or support. Some of the services needed (i.e. case management, and residential) are available to other disability groups, but are not available specifically for persons with a head injury. No state to date has developed a comprehensive statewide service delivery system addressing all the components for persons with head injuries and their families.

With regard to state services in Missouri it has been difficult for persons with head injuries to obtain long-term care and community support services from various state agencies due to eligibility requirements, availability of funding, and availability of services experienced in providing services to persons with head injury. Those persons who do have insurance or another third-party payer often find that their third-party coverage does not apply for long-term rehabilitation, long-term care and/or community support services. Yet, there is no state agency with specific responsibility for developing and providing those needed services or coordinating services through a case management system.

Prevention

The National Head Injury Foundation has coined the slogan, "The only cure for head injury is prevention," as the incidence and severity of head injury can be reduced through prevention and early intervention activities. Motor vehicle related accidents, bicycles, motorcycles, and off-road vehicles accounted for over half of all head injuries in Missouri in 1988. Falls account for nearly one-third of the injuries and are the second leading cause. Thirty-seven percent of injuries caused by falls occur among persons age 65+ and another 28 percent of injuries due to falls occur among children less than age 15. Diving accidents, industrial accidents, assaults, weapons and recreational accidents also cause head injuries.

Injury has traditionally been regarded primarily as an

unavoidable accident rather than a public health problem. However, injuries can be prevented with a variety of strategies. Three general strategies are available to prevent injuries: (1) *Persuade* persons at risk to alter their behavior, (2) *require* individual behavior change by law or administrative rule and (3) *provide* automatic protection by product and environment design.

In 1983, Congress enacted a law authorizing the secretary of the Department of Transportation to request a study on trauma injury by the National Academy of Sciences. The committee issued the report *Injury in America: A Continuing Health Problem* in 1985. One of the findings of the committee was the lack of the data necessary to allow for the study of the epidemiology of most injuries. The committee believed that systematic data collection is essential for planning and evaluating prevention programs.

In 1988, the U.S. House Committee on Appropriations encouraged the establishment of an Interagency Head Injury Task Force to identify the gaps in research, training and service delivery and recommend solutions in meeting the needs of persons with traumatic head injury. The Task Force released its report spring of 1989. In the report the Task Force made five recommendations with regard to primary prevention:

- 1.) Developing behavioral and environmental interventions aimed at reducing the frequency or severity of traumatic brain injury.
- 2.) Encouraging the use of both innovative and proven model prevention programs with provisions to evaluate their results.
- 3.) Encouraging activities that minimize head injury risk in athletics and stimulate the use of helmets (or other protective device) by boxers, bicyclists, motorcyclists, and other high-risk groups.
- 4.) Evaluating existing societal barriers to the effective implementation of prevention of strategies.
- 5.) Improving community-level access to existing database systems to assist in designing and developing prevention programs.

Emergency Medical & Medical Services

The outcome of injury depends not only on its severity, but also on the speed and appropriateness of treatment. Rehabilitation should first begin with the emergency medical services team at the scene of the accident. Proper attention should be provided in order to prevent further injury. Trained paramedics are able to attend to airways, treat shock, and monitor a patient's condition. They can also notify the receiving hospital regarding the patient's condition and the estimated time of arrival.

The emergency medical services system has improved over the years. Much of the improvements have been attributed to the military which has used triage methods at the scene of the accident and helicopters to transport severely injured patients to receive care in a minimum amount of time during military conflicts. "Communication systems are needed to facilitate decision making, injury management at the site, and the rapid delivery of the patient to a hospital that can provide the needed care,"

according to the report, *Injury in America: A Continuing Health Problem*.

The Federal Interagency Task Force recommends:

- (1) Enhancing the provision of emergency services through training, improved communications and availability of rapid transportation of the injured and
- (2) ensuring adequate geographical distribution of local acute care trauma facilities.

After the victim is attended to at the site of the accident, he or she is usually, then, transported to the hospital emergency department where the medical team tries to stabilize the patient as well as to diagnose the immediate problems. For more than a decade the American College of Surgeons has pushed for a regional system of hospital-based trauma centers. A trauma center is a hospital where the medical staff has made a commitment to provide 24-hour "in-house" coverage by surgeons, anesthesiologist and supporting staff to care for trauma patients.

Many patients with "minor" head injury may be discharged from the emergency department. (Such patients, however, may experience problems such as headaches, memory disturbances, confusion and disorientation.) For others who may be more severely injured, surgery may be performed for various reasons. After surgery, the patient may be moved to the intensive care unit for acute care until he no longer needs acute monitoring.

If the patient is comatose, he or she may be provided stimulation and physical therapy to prevent deformity or atrophy of the muscles and bones. If the patient appears to be in a persistent vegetative state, or emerging from coma, the hospital may discharge the patient to a nursing facility or to home for the family to provide or arrange for nursing care.

Rehabilitation

Rehabilitation refers to a comprehensive series of interventions for physical, medical, cognitive, psychological disabilities designed to restore a person to his or her maximum functional potential. This process should begin immediately after the injury as possible. Some general hospitals maintain a rehabilitation unit where physical, speech and occupational therapies are provided. As the patient progresses medically, he may receive such therapies and may be moved to a rehabilitation unit or a separate short-term rehabilitation hospital which, in addition, may also provide cognitive rehabilitation.

The patient may be evaluated by a team of professionals, including a neuropsychologist or psychologist, which, then, develops a rehabilitation program to address the patient's problems. These problems may be related to memory, attention, movement, balance, personality changes, difficulty with complex thinking and with judgment, inappropriate behavior, and difficulty with speech and language. Patients are usually discharged after reaching a plateau of recovery, although many may still require continued rehabilitation beyond the acute stage.

The Federal Interagency Task Force recommendations with regard to rehabilitation are:

- 1.) Encouraging the continuing review of standards of service for traumatic brain injury clinical care and rehabilitation by appropriate public and private organizations.
- 2.) Emphasizing outpatient rather than inpatient services for noncritical care and rely on outpatient services at the local level.
- 3.) Focusing on the ultimate goal of independent function in the community, including training in problem solving and incorporating proven behavior and educational therapies.
- 4.) Encouraging appropriate local and state agencies to mount special efforts to provide counseling for survivors of traumatic brain injury and their families; supportive resources such as day care; traumatic brain injury vocational counseling and training; and specialized treatment in the case of the traumatic brain injured with mental health, alcohol, and substance abuse problems.
- 5.) Utilizing for traumatic brain injury care appropriate mental health, mental retardation and special education facilities and programs.
- 6.) Facilitating community reentry by the provision of transitional and supervised residential facilities and programs. For those survivors whose recovery is delayed or incomplete, a wide range of residential settings is needed, from skilled nursing units to domiciliaries and semi-independent group living facilities.

The Missouri Head Injury Advisory Council has defined three types of head injury rehabilitation programs: (1) *Acute Brain Injury Rehabilitation*, (2) *Functional Living Rehabilitation* and (3) *Transitional Living Rehabilitation*. Most often, after traumatic head injury, the patient goes from acute medical care

to *acute rehabilitation* which focuses on physical and gross cognitive deficits. The program is designed to prevent and/or minimize chronic disabilities while restoring the individual to the optimal level of physical, cognitive and behavioral functioning. The rehabilitation program should be carefully coordinated and implemented as soon after onset of injury as is medically feasible.

Functional Living Rehabilitation Programs provide intensive rehabilitation with goal directed services to persons who have either completed acute rehabilitation or who have no major acute rehabilitation needs. Emphasis in this program is on functional cognitive, memory, or perceptual deficits, and appropriate interpersonal skills. Services may be delivered on an inpatient (residential) or outpatient (day program) basis.

Transitional Living Rehabilitation Programs provide intensive rehabilitation with goal directed services to persons who have sustained traumatic brain injury and who have completed acute and functional living rehabilitation programs or who have no significant need for such services prior to transitional living programs. In these programs, participants would typically move from close observation and supervision to independent living with minimal supervision. Transitional living programs may exist independently or may be part of a larger program. The program should provide safe, accessible housing which allows transition from group living situations to independent living. Housing facilities should include provision for 24-hour supervision.

The goal of rehabilitation is to enable a survivor of head injury to return to his/her employment/school and to his or her home environment. Many will return to work provided that certain modifications in the work environment take place which will enable the person to return to his or her job. Others will require extensive rehabilitation or programs which specialize in pre-vocational or vocational rehabilitation in order to be able to engage in competitive employment. For those who will not be able to engage in competitive employment without some type of assistance, other alternatives will need to be available.

Pre-vocational/Pre-employment Training readies a person for vocational rehabilitation. The program addresses behavioral and/or cognitive compensation strategies learned through cognitive rehabilitation and/or work adjustment training. This type of program often fills a gap between functional/transitional rehabilitation and vocational rehabilitation services provided by the Missouri Division of Voca-

tional Rehabilitation.

Vocational Rehabilitation readies a person for employment. The federal Rehabilitation Act of 1975 as amended is administered through the Missouri Department of Elementary and Secondary Education, Division of Vocational Rehabilitation. Vocational Rehabilitation is a program designed to help physically or mentally disabled persons become employable. Many services are provided under the federal program of which some are free and others assessed by the ability to pay. Some of the services made available to clients are as follows:

- 1.) A doctor's examination to assess the severity of the disability.
- 2.) Medical and hospital care to reduce the disability and improve changes for employment.
- 3.) The purchase of such items as artificial arms and legs, braces, wheelchairs or hearing aids to increase the ability to work.
- 4.) Job training. This may include college education, commercial or trade school, or on-the-job training.
- 5.) Work evaluation and adjustment.
- 6.) Transportation allowance while receiving medical treatment or job training arranged by the vocational rehabilitation counselor.
- 7.) An allowance sufficient for noon meals if job training is provided in the client's home community.
- 8.) The cost of room and board if job training is provided in the client's home community.
- 9.) Equipment needed for employment (including tools and a license if needed).
- 10.) Help in finding a job.
- 11.) Help in solving problems encountered on the job.

To be eligible for services through the Division of Vocational Rehabilitation a person must meet the following requirements:

- 1.) The presence of a physical or mental disability which for the individual constitutes or results in a substantial handicap to employment and
- 2.) A reasonable expectation that vocational rehabilitation services may benefit the individual in terms of employability.

Employment

Supported Employment refers to competitive employment occurring in integrated work settings and being performed by individuals with handicaps for whom either competitive employment has traditionally occurred or competitive employment has

been interrupted or become intermittent as the result of a severe disability and which, because of their handicaps, need ongoing job coaching, psycho-social and other support services to perform such work.

Sheltered Workshop Employment refers to an occupation-oriented facility operated by a not-for-profit corporation, which, except for its staff, employs only persons with a handicap and has a minimum enrollment of at least fifteen employable handicapped persons (Section 178.900 RSMo.). To be eligible persons must be certified by the Division of Vocational Rehabilitation.

Day Programs maintain the intellectual, emotional, social, vocational, and physical capacity of a person who may have received services from an acute rehabilitation, functional living rehabilitation and/or transitional living program, and is unable to maintain a job or participate in a vocational or educational program.

Residential Services

Ideally, a person suffering from a head injury would return to his/her natural environment following medical and rehabilitation care whether that be to live with a spouse, other family member(s) or independently/semi-independently. For those who are unable to return to his/her natural environment independently, then some type of housing or support which provides supervision and protection may be needed. Others may require continued rehabilitation, medical, or specialized care provided in a residential setting.

Home health care agencies provide three type of services: (1) In-home visits by nurses, which generally are covered by Medicaid or Medicare; (2) homemaker program providing non-medical assistance, such as grocery shopping, to elderly or handicapped persons who would otherwise be in nursing homes, which is a Medicaid service; and private duty (8 hours at a time), which is generally covered by private pay, insurance and sometimes Medicaid.

Personal Care Assistance provides in home assistance which may include help with dressing, bathing, eating or other personal care activities, thus enabling a person to reside in a semi-independent living situation.

Independent Living Centers may provide counseling and /or supervision on a periodic basis, thus

assisting the person with head injury to live semi-independently.

Supervised Living Arrangement is a place of residence that substitutes for the individual's own home or for the home of the individual's family. It should provide environments that are conducive to the development of adaptive behavior, self help and independent living skills. The residence also should facilitate, to the greatest possible extent, continuity with culturally normative living patterns. It should be located within the community and should include both generic and specialized services.

Structured Residential Placement provides 24-hour care and treatment for those individuals who manifest severe behavior problems. The setting may exist independently or as a part of a larger program.

Coma Management/Nursing Programs may accept such individuals once they are medically stable and attempt to achieve improvement by the use of various stimulus techniques. Skilled nursing care and physical therapy are important elements of these programs.

Respite Care provides temporary relief to the family, thus enabling the family to care for the person in his or her home.

Community Support Services

Community support services provide ongoing or intermittent support to survivors of head injury and their families following rehabilitation, thus, enabling them to live in the community on their own or with family or other assistance. These services may exist independently or be part of a larger program. Such services provide ongoing or intermittent support in several areas including recreation, counseling, transportation, therapies, and other support services. Case management has sometimes been categorized as a support service. As in other fields, case management is viewed by the Missouri Head Injury Advisory Council as playing a major role in the provision of services and should be addressed as a major component of the service delivery system.

Counseling is an individual or a family intervention to provide psychological support, direction, or change with regard to feelings or thoughts elicited or resulting from brain injury.

Family Training is a program of training for family members which provides skills to assist the person with a head injury in the family and outside of the home, emphasizing a program of structural activities. In essence, family members are trained to become their own service provider.

Follow-Up provides for the monitoring of clients who have returned to school, home or employment to program. It may be a component of a Functional Living Rehabilitation, Transitional Living or Pre-Vocational Training/Pre-Employment training program.

Transportation refers to the provision of necessary travel accommodations for persons with brain injury to and from places where they are employed or where they receive other services. Transportation may include the provision of driver's education, adaptive automobile devices, and/or training in the use of public transportation systems.

Recreation/Socialization activities may be provided in specialized programs specifically for persons with head injury or in existing community programs.

Case Management & Program Planning

Case management is an encompassing process which is the link between the client and the service delivery system. It is a method that analyzes client needs and assesses area resources in order to provide, procure, purchase, and coordinate services for persons with a brain injury. The process must be flexible to allow for the reformulation of service plans relative to changing client needs. It allows clients to remain in their least restrictive environment and fosters the concept of normalization. Case management generally consists of the following functions: (1) Intake; (2) service planning (developing an individualized rehabilitation plan); (3) service coordination; (4) service monitoring/quality assurance; (5) supportive counseling; and, (6) client advocacy.

Evaluation/Assessment services consist of the initial clinical interview for (1) determining the level of cognitive, speech/communication, independent living skills, emotional, physical and/or vocational functioning; (2) determining the need for rehabilitation or specialized service(s); (3) and/or development of a rehabilitation plan. An interdisciplinary team should provide the initial or ongoing assessment and de-

velop treatment/rehabilitation plans based upon the assessment. Initial or ongoing assessment should address the following:

- Medical and neurological issues
- Health and nutrition
- Sensorimotor capacity including gross and fine motor strength and control, sensation, balance, joint range of motion, mobility and function
- Cognitive capacity
- Perceptual capacity
- Communicative capacity
- Affect and mood
- Interpersonal and social skills
- Behavior
- Activities of daily living including self-care, home and community skills
- Recreation and leisure time skills
- Educational and/or vocational capacities

- Sexuality
- Family
- Legal competency of the person
- Community reintegration, including appropriate post-discharge services
- Environmental modification
- Adjustment to disability

Program Evaluation/Standards/Certification are the measures against which a program organization or agency is compared to monitor and assess its common practices, quality, and effectiveness in carrying out program and client goals and objectives. The Commission on Accreditation of Rehabilitation Facilities (CARF) has developed national standards for some types of brain injury programs. The standards are voluntary and an agency can apply to CARF for accreditation.

The Current System of Services

Prevention

Head Injury Registry

The Missouri Department of Health implemented the head and spinal cord injury registry July 1, 1987, as the result of legislation which passed during the 1986 legislative session requiring all hospitals to report all head and spinal cord injuries to the department. The department is to, in turn, report at least annually data regarding head injuries to the Missouri Head Injury Advisory Council. That information will allow the state to be in a position to study and address the extent of injury in Missouri and the effectiveness of laws and educational programs directed toward the prevention of injuries. (The registry data will also allow the state to assess emergency medical services and hospital care and treatment as well as the extent of injuries and the resulting disabilities.)

Missouri is unique in that the state has five data systems which other states do not have: Missouri Head and Spinal Cord Injury Registry, Statewide Trafficway Accident Reporting System (STARS), Missouri Ambulance Reporting System (MARS), Hospital Admissions System, and the Death Certificates System. Four of these systems are administered by the Department of Health. The fifth system, STARS, is administered by the Missouri State Highway Patrol.

In February 1989, the Missouri Department of Health received notice of approval of two grants from the National Highway Traffic Safety Administration to link these five data systems for purposes of researching costs of injuries as the result of motor vehicle accidents; contributing factors such as lack of seat belt use, speed, etc.; effectiveness of the emergency medical services system; and so forth. Missouri is one of four states to receive a contract to link data systems from the scene of the accident to the hospital emergency department. It is the only state to receive an additional contract to collect cost data after hospital discharge. The department will conduct the study in cooperation with the Division of Highway Safety, Missouri Highway Patrol Statistical Analysis Center, the Missouri Head Injury Advisory Council and the Missouri Hospital Association.

State Laws

Missouri has several laws designed to reduce fatalities and injuries including: mandatory seat belt law for occupants in the front seat of automobiles, child safety restraints for children under the age of four, motorcycle helmet usage law for all riders, and severe penalties for DWI (Drinking While Intoxicated). In addition, Missouri has passed legislation requiring all ATV (all terrain vehicle) drivers under the age of 18 to wear a helmet and persons under the age of 16 must be supervised by an adult.

Public Education/Prevention Programs

The Missouri Head and Spinal Cord Injury Prevention Project, University of Missouri-Columbia, conducts school assemblies addressing the need for exercising good judgment in order to avoid unnecessary accidents. The Project assisted in the making a nationally acclaimed, award winning film called *Harm's Way* featuring young adults from Missouri with head and spinal cord injuries. The prevention program has been modeled in various parts of the state, as well as nationally. The Council has supported expanding the program statewide and has supported the program in its efforts to evaluate the effectiveness of the program. The program receives financial assistance from the Missouri Department of Health, Missouri Division of Highway Safety, the Missouri Safety Belt Coalition and other sources.

The SAFE KIDS program, a national coalition of 65 civic and health organizations was formed to focus on childhood injury. Initiated by Children's Hospital National Medical Center, Washington, D.C., the campaign is supported by Johnson & Johnson and the National Safety Council. During the past year, the program focused on bicycle safety. In Missouri, there is a statewide coalition and several local SAFE KIDS Campaigns. Cities which have coalitions include Columbia, Kansas City, St. Louis and Springfield.

The National Head Injury Foundation has joined with the American Academy of Pediatrics and the Bicycle Federation of America to launch Head Smart, a national campaign to prevent head injuries through increased use of approved bicycle helmets. Material to promote local awareness is available through the Foundation and its state chapter, the Missouri Head Injury Association.

The Children's Trust Fund, funded through donations, is the principal funder of child abuse prevention programs and plans to spend between \$500,000 to \$600,000 in Fiscal Year 1990. Statewide about \$70 million will be spent by the Missouri Department of Social Services for children's protective services and the investigation and treatment of child abuse. Of that, \$25 million will be for foster and residential care.

The Missouri Department of Health, Division of Health Resources, applied to Centers for Disease Control for a three year grant to establish a state injury prevention section within the division. The division received notice of award September 1989. The section will coordinate prevention programs, evalu-

ate prevention efforts, and coordinate state policy with regard to injury prevention.

Other educational efforts regarding safety are conducted statewide and locally by or with support from the Missouri State Highway Patrol, the Missouri Safety Belt Coalition, Missouri Safety Council, and the Missouri Division of Highway Safety.

Emergency Medical & Medical Services

Trauma Center System

Until legislation passed during the 1987 session, Missouri's trauma center system was voluntary on the part of the hospitals. The Missouri Department of Health developed Trauma Triage Protocol to assist emergency department personnel in the treatment of trauma patients. Like the trauma center program, this protocol was voluntary.

The legislation which establishes a trauma center system requires the department to develop criteria for a trauma center and to designate trauma centers after on site review. The legislation also requires licensure of air ambulances and requires all ambulances to transport seriously injured patients to the closest designated trauma center or hospital according to protocol developed by the department. The legislation established the State Emergency Medical Services Council statutorily which is to assist the department with developing rules and regulations necessary to implement the new requirements and to continue to develop recommendations for improving the emergency medical services system.

The Division of Health Resources with input from the State Emergency Medical Services Council drafted regulations regarding criteria for trauma center designation and the rules and regulations are in the process of being reviewed. Trauma centers have been reviewed and designated across the state.

Three levels of trauma services have been delineated. The Level I is one that has made a large commitment in personnel and equipment to care for the trauma patient. The principal difference between Level I and Level II is the availability of staff specialists. A Level II hospital is most likely to be in a geographic area which lacks a hospital with resources of a Level I. The Level III hospital will most often have 100 to 250 beds in a community that lacks hospitals of Level I or II capability. Hospitals designated as

trauma centers include the hospitals listed below.

Level I

Columbia

University of Missouri Hospital and Clinics

Kansas City

St. Luke's Hospital
Truman Medical Center (Adult only)
Children's Mercy Hospital (Pediatric only)

St. Louis

Barnes Hospital (Adult only)
St. Louis Children's Hospital (Pediatric only)
St. John's Mercy Medical Center
St. Louis University Hospital (Adult only)
Cardinal Glennon Children's Hospital (Pediatric only)

Level II

Cape Girardeau

St. Francis Medical Center
Southeast Missouri Hospital

Clinton

Golden Valley Memorial Hospital

Columbia

Boone Hospital Center

Joplin

Freeman Hospital
St. John's Regional Medical Center

Kansas City

Research Medical Center
St. Joseph Health Center

Kirksville

Kirksville Osteopathic Hospital Unit

Liberty

Liberty Hospital

North Kansas City

North Kansas City Hospital

Osage Beach

Lake of the Ozarks General Hospital

Poplar Bluff

Doctor's Regional Medical Center

Rolla

Phelps Co. Regional Medical Center

St. Charles

St. Joseph Health Center

St. Joseph

Heartland Hospital East

St. Louis County

Christian Hospital Northeast
DePaul Health Center
St. Anthony's Medical Center

St. Louis

Missouri Delta Medical Center

Springfield

Lester Cox Medical Center South
St. John's Regional Health Center

Level III

Aurora

Aurora Community Hospital

Bolivar

Citizens Memorial Hospital

Branson

Skaggs Community Hospital

Farmington

Mineral Area Osteopathic Hospital

Festus

Jefferson Memorial Hospital

Hannibal

Hannibal Regional Health Care System

Houston

Texas County Memorial Hospital

Jefferson City

Charles E. Still Hospital
Memorial Community Hospital
St. Mary's Health Center

Joplin

Oak Hill Hospital

Kansas City

Park Lane Medical Center
Trinity Lutheran Hospital

Kennett

Twin Rivers Regional Medical Center

Marshall

John Fitzgibbon Memorial Hospital

Maryville

St. Francis Hospital

Mexico

Audrain Medical Center

Moberly

Moberly Regional Medical Center

Poplar Bluff

Lucy Lee Hospital

Smithville

Spelman Memorial Hospital

Springfield

Lester Co Medical Center North

Troy

Lincoln County Memorial Hospital

West Plains

Ozarks Medical Center

The head and spinal cord injury registry data not only collects data with regard to the number of injuries, but also with regard to method of transportation, length of time in the emergency department, medical treatment provided, disposition of the patient and so forth. Through data collected from the registry, the Department of Health is able to provide hospitals a report listing specific cases identified by audit filters that hospital quality assurance committees may want to review and to take action in order to remediate any potential problem in the emergency and medical care service delivery system.

The Department of Health, Division of Health Resources, through its Bureau of Emergency Medical Services administers the State Ambulance Licensure Law. Its programs includes: (1) Review and approval of curricula at training facilities that offer courses for emergency medical technicians (EMT), mobile emergency medical technicians (MEMT), emergency medical technician paramedics (EMT-P), first responder and corresponding refreshers courses; (2) develop/administer uniform EMT and MEMT certification tests; and (3) develop and coordinate a statewide EMS communications systems.

The statewide emergency medical communications systems includes 141 hospitals with two-way radio capabilities for communicating with ambulances. This system enables an ambulance attendant to radio a hospital to receive advice from a physician or other emergency department personnel concerning care of an emergency patient that the ambulance transporting.

Rehabilitation Services

Acute, Functional and Transitional Rehabilitation

Rehabilitation programs for survivors of head injury are relatively new. Most of the programs providing services are private facilities. Several hospitals provide acute rehabilitation and outpatient rehabilitation services such as speech therapy, physical therapy and occupational therapy on a limited basis. A few hospitals and rehabilitation facilities provide functional living rehabilitation services. Most of the programs require the patient or client to have the ability to pay for services or have access to third party pay such as insurance or worker's compensation. For those who do not have the ability to pay, the financial resources are limited.

The Missouri Medicaid program provides very little reimbursement for outpatient therapy services. However, legislation passed during the 1988, session which not only expanded Medicaid eligibility for children, also expanded services to include comprehensive day rehabilitation, defined as post acute (functional living) rehabilitation for trauma patients. It is anticipated that seven or eight programs throughout the state may enroll in the Medicaid program to provide this type of service during FY'90.

As the result of legislation passed during the 1985

session, the name of the State Chest Hospital was changed to the Missouri Rehabilitation Center. The facility, administered by the Missouri Department of Health, is located in Mt. Vernon. A head injury unit was established January 1986 from a state appropriation designated for that purpose. The Missouri Rehabilitation Center provides acute rehabilitation, functional living (residential) and transitional rehabilitation programs.

Also during the 1985 session, an appropriation (\$500,000) was made to the Department of Health for purposes of purchasing services for survivors of head injury during FY'86. For FY'87 the program was reduced to \$226,361. The department administered the program for two years, then requested that the appropriation be transferred to the Office of Administration, Division of General Services. The appropriation for contractual services for FY'88 was increased to \$314,685. The same amount was appropriated for FY'89 and for FY'90 the Office of Administration, Division of General Services received an additional \$207,000 for head injury services.

After the program was transferred July 1, 1987, the Office of Administration extended contracts to Rusk Rehabilitation Center, Columbia, and Truman Medical Center-East, Kansas City, for functional rehabilitation services and both programs received a new contract for FY'89. Both programs provide services on an outpatient basis. Both Rusk Rehabilitation Center through its Brain Injury Rehabilitation Program and the Transitional Learning Center at Truman Medical Center-East serve eight clients on a daily basis.

Private programs which provide functional living rehabilitation services include Rebound, Inc., a health care corporation, located in Lee's Summit, and HEALTHSOUTH Rehabilitation Center, St. Louis, a publicly-traded corporation. Both of these programs offer other types of services for persons with head injury. HEALTHSOUTH operates two facilities, one is an outpatient rehabilitation facility, and the other offers acute rehabilitation, transitional programming, respite care, coma management, and subacute rehabilitation.

SSM Rehabilitation Institute, a not-for-profit rehabilitation facility operating facilities in St. Louis and St. Charles, also offers functional living rehabilitation services. SSM is developing a pediatric rehabilitation program. Irene Walter Johnson operated by the Washington University Medical Center opened the Head Injury Resource Center in March 1986, offering

functional living rehabilitation services as well as pre-vocational training and job placement. These services are offered in an outpatient setting.

Rebound, Inc., broke ground in the spring of 1988 to construct a 40 bed transitional living center. The transitional program is designed for the higher functioning individual in preparation for community re-entry. Rebound accepts clients with the ability to pay or who have access to third party pay such as insurance or worker's compensation.

During March 1989, Bethesda General Hospital, St. Louis, announced a new head injury rehabilitation program offered in cooperation with Premiercare Rehabilitation Center, a Massachusetts based company specializing in the development and management of Neuro Rehabilitation Programs. The Premiercare Program provides intensive therapies in the areas of physical therapy, speech and language therapy, cognitive therapy and occupational therapy. The 28 bed dedicated unit has medical services provided by the Department of Neurology at St. Louis University School of Medicine.

Rehabilitation Network, St. Louis, offers outpatient therapies for persons with head injury. The services are provided in the home and a head injury program is available at the Network's facility. Several hospitals around the state offer varying types of services for persons with head injury.

Pre-Vocational & Vocational Rehabilitation

A day program was established in St. Louis by the Bi-State Chapter of the Missouri Head Injury Association with funding from the head injury state appropriation, presently being administered by the Missouri Office of Administration, Division of General Services, in FY'86. The program provides a variety of day program activities to ten persons three days a week.

Advent Enterprises, Inc., a not-for-profit corporation in Columbia, provides pre-vocational/employment training and is under contract with the Office of Administration, Division of General Services to provide services to approximately six persons at one given time. Blue Valley Head Injury Center, a not-for-profit organization, opened a program during the summer of 1988 designed to provide a sheltered workshop environment to assist clients to learn the work skills

necessary to re-enter the community workforce. In the event community employment is not possible due to the severity of the client's deficits, the person can continue to work in the sheltered workshop environment. The program contracts with the Division of Vocational Rehabilitation for work adjustment services.

Blue Valley is not certified by the Missouri Department of Elementary and Secondary Education, Division of Special Education, as a sheltered workshop eligible for state sheltered workshop subsidy. The division does not allow sheltered workshops to be established for one specific disability group.

The Division of Vocational Rehabilitation has assigned a vocational rehabilitation counselor in each district office to work with clients with head injury. The division provides on going in-service training regarding head injury to its counselors to assist them in securing appropriate vocational services for survivors of head injury. The division purchases services for its clients from vendors rather than providing direct services.

The first vocational rehabilitation program recognized as expanding its services to head injured clients is Metropolitan Employment Rehabilitation Services, St. Louis, with assistance from the division. The division also obtains vocational training services for clients with head injury from the following agencies: Advent Enterprises, Columbia; Goodwill Industries, St. Louis; Life Skills Foundation, St. Louis; and Rehabilitation Institute, Kansas City.

Through a cooperative effort involving Truman Medical Center-East and Rehabilitation Institute, both of Kansas City, and the Division of Vocational Rehabilitation, a job training program was developed for persons with head injury in the Kansas City area. Graduates of the Transitional Learning Center, Truman Medical Center-East, and other potential candidates for the job training program referred to the division for job placement are evaluated by the Rehabilitation Institute.

Those eligible are placed in temporary hospital jobs at Truman Medical Center. Job coaches are provided by Rehabilitation Institute with funding from the division. Job performance is monitored by the Transitional Learning Center staff. Duration of the temporary positions range from three to six months and the trainees receive wages.

Supported Work

The Missouri Division of Vocational Rehabilitation receives federal funding for time limited supported work programs. One of the requirements is a demonstration that long term support is available to assist the person in maintaining employment before federal dollars can be used.

Supported work programs have developed in Missouri for persons with developmental disabilities or mental illness as the Missouri Department of Mental Health and local mill tax boards are able to make some commitment for long-term support. However, supported work funding has not been readily available for persons with head injury due to the lack of assurance for long-term support.

During the 1989 legislative session, additional funding was appropriated to the Missouri Office of Administration, Division of General Services for long-term support services to enable persons with head injury to participate in the supported work program funded initially by the Missouri Division of General Services.

The Office of Administration, Division of Purchasing issued a Request For Proposal (RFP) in May 1989, soliciting long-term support programs. With the state commitment for long-term support more persons with head injury will be able to participate in the program and will have the necessary support to maintain employment over the long term following completion of supported work program initially funded by the Division of Vocational Rehabilitation.

Education

The Missouri Department of Elementary and Secondary Education, Division of Special Education, has assigned staff to assist school districts with the provision of educational services to students with head injury. The division has prepared a manual, *Developing Individual Education Plans for Students Who Have Suffered Traumatic Head Injury*, outlining educational responsibilities to be used in conjunction with the manual developed by the National Head Injury Foundation.

Staff from the division is working with the Department of Health, Division of Health Resources, and others to identify the number of school aged children with head injuries.

Residential Services

Personal Care Assistance/ Independent Living Centers

There are five independent living centers throughout the state which provide in varying degrees personal care, in-home care and other independent living services to persons with disabilities. Some of the centers do offer their services to persons with head injury. State funding is appropriated to the Missouri Division of Vocational Rehabilitation for personal care attendant services. The independent living centers administer these funds at the local level. Services have been limited due to the appropriation.

Services for Independent Living, an independent living program in Columbia formerly known as Opportunities Unlimited, is under contract with the Missouri Office of Administration, Division of General Services, to provide in-home, counseling and other supervision for those living independently/semi-independently. Some of the home health care agencies also provide in-home care (medical) and homemaker services for persons needing such care in the community.

Supervised Residential Programs

Supervised residential programs (apartment living or group homes) providing long term housing have yet to be developed for survivors of head injury in Missouri. Persons requiring long term care or specialized care have generally sought services from the Missouri Department of Mental Health through its Division of Comprehensive Psychiatric Services and Division of Mental Retardation and Developmental Disabilities and from nursing homes. Some have sought services outside of Missouri. Interest has been expressed in developing supervised living arrangements for persons with head injury, but funding has yet to be secured for this type of service.

Structured Residential Placement

St. Louis State Hospital, a facility operated by the Missouri Department of Mental Health, has developed a head injury unit to serve some head injury patients with aggressive or severe behavior problems. The unit is for men only as the facility does not have the staff to develop a separate program for both

men and women. The unit is housed on a ward at the hospital and was originally established to serve the hospital's patients with head injury who had been at the hospital for some time and did not benefit from treatment for mentally ill patients. Some of the patients have been discharged and the unit now accepts referrals. During the 1989 legislative session, the Missouri Rehabilitation Center, operated by the Missouri Department of Health, received funding for four beds for persons with head injury with severe behavior problems.

The Department of Mental Health and the Department of Health is developing an interagency agreement which will define the level of disability and behavior accepted by the Missouri Rehabilitation Center and the St. Louis State Hospital and how both facilities will coordinate services.

Generally, persons with head injury who also exhibit aggressive and inappropriate behavior find it difficult to locate programs which will accept them due to lack of staff or adequate facility or both. The commitment law which allows the court to commit mentally ill persons who are considered dangerous to self or others does not apply to persons with head injury.

Coma Management Programs

Although the Missouri Rehabilitation Center has a few clients who are comatose or in a semi-coma, the facility has not held itself out as having a coma management program. A few nursing homes have accepted patients coming out of coma, but generally the nursing home industry does not believe nursing homes have the staff, in part, due to the costs and reimbursement, to handle this level of care. St. John's Hospital in St. Louis has recently developed a coma management unit and SSM Rehabilitation Institute and Rebound, Inc. accept coma patients.

Support Services

Recreation

The Missouri Head Injury Association sponsors a camp, Wilderness Retreat, during the summer with some assistance from the state through a contract with the Missouri Office of Administration, Division of General Services. The camp, which consists of two one-week sessions, not only provides socialization and recreation for those who have sustained a head injury, but also provides respite for their families and

caretakers.

Counseling/Family Support/Referral

Some families and persons with head injury seek counseling services through community mental health centers throughout the state and from private counseling services. The Missouri Head Injury Association through its local chapters offer family support and referral services. The council also provides referral services.

Case Management & Program Planning

Ideally, case managers for persons with head injury would be available throughout the state to assist families and survivors in accessing services and funding necessary for the client to receive rehabilitation and/or to remain in the community. Although case management services are provided by some individual providers, case management is not provided, generally, independent of providers for persons with head injury. For persons who meet the eligibility criteria for the Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, case management services are provided through the division's eleven regional centers for the developmentally disabled. However, services which may be prescribed by the regional centers' treatment team may not be available for persons with head injury so that the clients with head injury may be either referred to programs for persons with developmental disabilities or are not provided services.

Programs under contract with the Missouri Office of Administration, Division of General Services are required to develop and implement individual treatment/rehabilitation plans according to guidelines provided in the contract. Facility standards with regard to fire and safety are also included in the contracts for programs to meet. The Commission on Accreditation of Rehabilitation Facilities has developed standards for brain injury rehabilitation (acute and outpatient) programs and facilities may subscribe to the standards. The Missouri Department of Social Services, Division of Aging, licenses nursing homes and the Missouri Department of Health licenses hospitals and rehabilitation hospitals. There are no state standards or licensing requirements for residential programs, day programs or other specialized services serving clients with head injury.

ACTION PLAN UPDATE

Summary of Council Activities

The Missouri Head Injury Advisory Council met five times during Fiscal Year 1989. At its September meeting the council re-elected Judy Ferguson and Representative Sheila Lumpe as chairman and vice-chairman. Mrs. Ferguson appointed five committees to facilitate council business. In addition, she appointed a Task Force on Service Delivery System to study and recommend which state agency should have primary responsibility for services and programs for persons with head injury who are ineligible to receive services provided by other agencies. The council recommended that legislation be filed giving the Department of Health the responsibility of developing and providing services built on a case management system. The bill, which passed the Missouri Senate, failed in the Missouri House of Representatives by only three votes.

At the direction of the council the University of Missouri Bureau of Media Research conducted a statewide random telephone poll to determine Missourians' knowledge of head injury and prevalence of head injury. Such information has not been available nationally. The council also worked with the Missouri Department of Health, the Missouri Division of Highway Safety and others for the Department of Health to obtain federal contracts from the National Highway Traffic Safety Administration to

link data systems to study the costs associated with injury and to obtain a grant from the Centers for Disease Control to establish a state injury control program.

The Missouri Office of Administration, Division of General Services received an additional state appropriation for long-term support services to enable persons with head injury to participate in the supported program which is initially funded by the Missouri Division of Vocational Rehabilitation. The Division of Vocational Rehabilitation provides funding for time-limited services including job assessment, job training, job placement and job coaching. Long-term support, such as job coaching, must be available in order for the person to be able to maintain employment after funding from the federal vocational program has been expended. This represents a new service for survivors of head injury. The council planned for an in-service training workshop for supported work providers and long-term support providers for October 1989.

The council sponsored its fourth annual statewide conference, "Building Service Delivery Systems for the 90's", in May 1989. It continued to publish a quarterly newsletter which is mailed to 4,000 people and to provide information and referral resources.

Issue 1: Prevention

Background

The incidence and severity of head injury can be reduced through prevention and early intervention activities. Half of all head injuries are caused by automobile accidents. The other half are due to recreational accidents, assaults, weapons, falls, and industrial accidents. Injuries have traditionally been viewed as unavoidable accidents rather than a health problem. Yet, injuries are the leading cause of death and disability in children and young adults and cause the loss of more working years than all forms of

cancer and heart disease combined.

Three general strategies are available to prevent injuries: (1) Persuade persons at risk to alter their behavior, (2) require individual behavior change by law or administrative rule and (3) provide automatic protection by product and environment design. In 1983, Congress enacted a law authorizing the secretary of the Department of Transportation to request a study on trauma (injury) by the National Academy of Sciences. The committee issued a report in 1985, *Injury in America: A Continuing Health Problem*.

Injury In America

One of the findings of the committee was the lack of data necessary to allow for the study of the epidemiology of most injuries. There is no national mechanism for collecting data regarding the number of head injuries, causes, number of persons disabled due to head injury and so forth. The committee believed that systematic data collection is essential for planning and evaluating prevention programs.

Also addressed in the report is the need for good emergency medical systems and medical treatment. The outcome of injury depends not only on its severity, but also the speed and appropriateness of treatment. In order to minimize injury, it is important to have a system in place which can allow for injury management at the scene of the accident and facilitate rapid delivery of the patient to a hospital which can provide the needed care.

Often referred to as the "golden hour," medical care provided to the patient during the sixty minutes following the accident is critical and often determines whether the patient survives the injuries. Designated trauma centers are vital to the system. Once a severely injured person arrives at a hospital, he or she will generally need the services of various specialists experienced in injury management.

The University of Missouri-Kansas City in cooperation with Argus Computing, Inc. developed a pilot trauma/injury database January 1986. Three hospitals participate in the Kansas City project and record all trauma, not just head trauma. The UM-KC project was developed independently of the Missouri Head Injury Advisory Council. The project staff, however, are very cooperative and supply data to the council on request. The staff also participated in the development of the state reporting form for the head and spinal cord injury registry and assisted the Department of Health with the in-service training for hospital personnel with regard to the completion of the form.

State Laws

Missouri has several laws designed to reduce fatalities and injuries. These laws include: Mandatory child restraints, mandatory seat belts for passengers in the front seat of automobiles, mandatory helmets for motorcycle riders, and stiff penalties for DWI (Driving While Intoxicated). Legislation passed during the 1988 session addressing safety for riders of ATVs (all terrain vehicles). Legislation also passed during the 1988 session repealing the sunset provision of the seat belt law.

There are several education programs promoting safety habits conducted by local and state agencies including: Missouri Division of Highway Safety, Missouri State Highway Patrol, Missouri Safety Belt Coalition, Missouri Safety Council, SAFE Kids, and the Missouri Head and Spinal Cord Injury Prevention Project, conducted by the University of Missouri-Columbia, and regional head and spinal cord injury prevention projects replicating the program developed by the University of Missouri-Columbia.

Accomplishments

The Missouri Head Injury Advisory Council co-sponsored with the University of Missouri a conference on prevention October 1985. The conference allowed for the discussion of Missouri's ability to gather data, its emergency medical services program, trauma center status, and programs focusing on prevention activities.

Head Injury Registry

During the 1986 legislative session, the council initiated legislation, which passed, mandating hospitals to report head and spinal cord injuries to the Department of Health, which in turn, is to report head injury data to the Missouri Head Injury Advisory Council. During FY'87, the council worked with the Department of Health and others to develop the reporting form. The registry was implemented by the department July 1, 1987. The department has provided in-service to the hospitals with regard to completion of the form and has continued to work with the hospitals to obtain consistency in reporting. The department will collect the data on a calendar year basis and will report accordingly. Data is now available from calendar year 1988.

Data Linkages

With assistance from the Missouri Division of Highway Safety and support from the Missouri Head Injury Advisory Council the Missouri Department of Health received two contracts from the National Highway Traffic Safety Administration for purposes of researching costs injuries as the result of motor vehicle accidents. Missouri is one of four states to receive a contract to link data systems from the scene of the accident to the hospital emergency department. It is the only state to receive an additional contract to collect cost data not only from the accident scene, but also from the emergency room

through hospital discharge. The department will survey a selected group of patients after hospital discharge to see what additional services, if any, the person has received. The department will conduct the three year study in cooperation with the Division of Highway Safety, Missouri Highway Patrol Statistical Analysis Center, Missouri Hospital Association and the Missouri Head Injury Advisory Council.

Head Injury Survey

During FY'88, the council initiated a head injury survey conducted by the University of Missouri, School of Journalism, Bureau of Media Research. The Bureau is conducting a statewide telephone poll to determine Missourians' level of knowledge of head injury, its causes and consequences. The poll may provide prevalence data which has not been determined in Missouri. The survey results are to be available during the fall of 1988.

Prevention Education

The council has supported the Missouri Head and Spinal Cord Injury Prevention Project in its efforts to inform public school students as to the need for exercising caution and good judgment in order to prevent unnecessary injuries. The council has advocated for federal funding and for state funding to evaluate the effectiveness of the program and to expand the program.

During the 1988 session, the council co-sponsored with other safety groups a breakfast for legislators featuring the prevention project. Members of the council testified before the Missouri Board of Health and the House Appropriations Committee on Mental Health for state funding for the program. The Department of Health received state funding for the first time in Fiscal Year 1988 for purposes of expanding the program. The program, which has expanded largely through local efforts, has been replicated in Kansas City, St. Louis, Cape Girardeau, Springfield and Joplin.

Also, the council networks with other safety groups with prevention efforts including the Missouri Division of Highway Safety Missouri Safety Council and the Missouri Safety Belt Coalition, of which the council is a member. In June 1986 the council director and two council members addressed the state and local safety councils as to how to use head injury data in their safety campaigns.

The council also worked with the various safety

groups to compile information supporting helmet and seat belt use. The sunset provision of the seat belt law was repealed during the 1988 session. The council has joined the national campaign, 70 by 90, which is striving to meet 70 percent correct child safety seat and adult safety belt use by 1990.

Public Information

Since January 1986, the council has published a newsletter called the *Quarterly*. It has sponsored four major conferences held annually in the spring beginning 1986: *Head Injury: Meeting the Challenges*, *Head Injury: Focus on the Future*, *Head Injury: From Injury to Independence*, and *Building Service Delivery Systems for the 90's*. The council has developed a brochure and display board to use at conferences. The council maintains resource files and distributes information on request.

Council staff arranged the Governor's proclamation proclaiming October as Head Injury Awareness Month. The previous fiscal year, the council staff arranged the Governor's proclamation and the Missouri House of Representatives and Senate courtesy resolutions honoring the Run to Daylight campaign, a head injury awareness project conducted on behalf of the National Head Injury Foundation in May 1989. Also during that year, the council also arranged for a state senatorial resolution recognizing February 7-13 as National Child Passenger Safety Awareness Week.

Trauma Centers

The council studied Missouri's voluntary trauma center system during FY'86. The council initiated legislation, which passed, during the 1987 session which establishes and regulate trauma centers. It also instructs ambulances to bypass the nearest hospital in order to transport a severely injured patient to a trauma center, further defines what EMTs may do at the scene of an accident for a seriously injured victim and requires licensure for air ambulances.

The Department of Health, Division of Health Resources reported routinely to the council with regard to the status of the department regulations. The proposed regulations are requiring all trauma centers to complete a trauma registry form which would record all types of trauma, including head injuries. The department is proposing to use the same form as the current head and spinal cord injury registry and expand it as necessary.

Plan Initiatives

Public Safety Legislation

Five-Year Goal: To support legislation which reduces fatalities and injuries.

First-Year Through Fifth-Year Objectives

Fiscal Year 1989-1993

1. To continue to oppose the helmet repeal.
2. To continue to oppose the seat belt repeal in cars and to support seat belts in trucks.
3. To continue to support legislation prohibiting children from riding in the back of pickup trucks.
4. To continue to study the issue of seat belts for school buses.
5. To support legislation which strengthens the DWI law by eliminating hardship drivers license's and lowering the blood alcohol content from .13 to .10 for administrative revocation.
6. Support legislation requiring children to wear bicycle helmets.

Progress in Meeting FY'89 Objectives: The council supported legislation requiring seat belts in pickup trucks, and opposed the helmet repeal legislation. The council and other safety organizations the year before developed a brochure regarding motorcycle helmets.

Public Information & Education

Five-Year Goal: To inform the public of the causes and treatment/rehabilitation of head injuries.

First- through Fifth-Year Objectives

Fiscal Year 1989-1993

1. To continue publishing the newsletter, press releases and other informational materials.
2. To maintain a resource file on current literature and audio-visual materials.
4. To develop a speaker's bureau in coordination with the Missouri Head Injury Association.
5. To develop brochures regarding the incidence and causes of head injuries in Missouri.

6. To encourage other organizations promoting safety to incorporate facts on head injury along with fatalities in their educational efforts.
7. To develop materials for interested groups/organizations to promote October Head Injury Awareness Month.
8. To continue to support funding to allow the Missouri Head and Spinal Cord Injury Prevention Project operated by the University of Missouri-Columbia to expand statewide.
9. To encourage school districts to invite the Missouri Head and Spinal Cord Injury Prevention Project to conduct its program during school assemblies.
10. To include prevention on the agenda of the annual council conference.

Progress in Meeting FY'89 Objectives: The council testified before the Missouri Board of Health in support of additional funding within the budget of the Department of Health for the prevention program and before the House Appropriation Committee on Mental Health and Health. The Department of Health for the second year received \$10,000 (GR) for the program. This represents the only state money toward the program which also receives federal funds from the Prevention Health Block Grant administered by the department and federal funds from the Division of Highway Safety as well as funding from other private agencies. The council continued publishing the newsletter, issued press releases, and appeared on radio and television news segments. The council office maintains a resource file and distributes information regularly. The council participated in the proclamation signing proclaiming October as Head Injury Awareness Month. A panel on bicycle safety was included during the Fourth Missouri Head Injury Advisory Council Annual Conference held in May 1989.

Two-Year Goal: To determine incidence and prevalence of head injury.

Second-Year Objectives

Fiscal Year 1989

1. Using data from the trauma registry, determine the primary causes of injuries in Missouri, the number of injuries, the severity of injuries, and possibly the prevalence of head injury.

Progress in Meeting FY'89 Objective: The Office of Administration, Division of General Services, at the direction of the council entered into contract with the University of Missouri-Columbia, School of Journalism, Bureau of Media Research, to conduct a statewide poll. The results provided prevalence data. The Department of Health has released information from the Missouri Head and Spinal Cord Injury Registry representing data collected in calendar year 1988. The information was presented during the Fourth Annual Missouri Head Injury Advisory Council Conference and has been routinely presented to the council at its meetings.

Incidence of Head Injury

Effectiveness of Prevention Programs

Three-Year Goal: To determine effectiveness of prevention programs.

Third-Year Objectives

Fiscal Year 1991

1. Using registry data and other informational systems, study the effectiveness of prevention programs and legislation designed to prevent injuries and fatalities.
2. Work with the University of Missouri-Columbia to study effectiveness of the Missouri Head and Spinal Cord Injury Prevention Project.
3. Work with the new Missouri Injury Control Program to evaluate effectiveness of head injury prevention programs.

Progress in Meeting FY'89 Objectives: The council has written several letters supporting grant applications submitted by the Department of Health and the University of Missouri-Columbia for purposes of evaluating the effectiveness of prevention programs, specifically the program conducted by the University. The Department of Health submitted an injury control grant to Centers for Disease Control for purposes of establishing a state injury control program which would be comprised of staff and an injury control council to plan, evaluate and coordinate injury prevention projects. CDC has awarded the grant beginning federal Fiscal Year 1990.

The council supported the Missouri Division of Highway Safety and the Department of Health in their quest to obtain funding to link five data systems enabling the department to study injuries and associated costs. The National Highway Traffic Safety Administration awarded the department two contracts to conduct the study.

The five data systems to be linked include: Missouri Head and Spinal Cord Injury Registry, Statewide Trafficway Accident Reporting System (STARS), Missouri Ambulance Reporting System (MARS), Hospital Admissions System, and the Death Certificates System. During the winter of 1989, the department linked three of the data systems and is in the process of linking the other two.

Trauma Centers

Three-Year Goal: To improve system of trauma care statewide.

Third-Year Objectives

Fiscal Year 1991

1. Using data from the registry, work with the Department of Health and the State Emergency Medical Services Council to study the effectiveness of Missouri's emergency medical system and the trauma center system.
2. Support the Department of Health and the Missouri Advisory Council on Emergency Medical Services in their efforts to improve the state trauma center system.

Issue 2: Planning for a Statewide Service Delivery System

Background

Programs for survivors of head injury and their families are relatively new with the majority of programs, mostly private, having been developed the past ten years. No state has developed a comprehensive statewide service system, although many states have established councils or task forces to address planning and have begun funding services on a limited basis.

Head Injury Council

The state of Missouri began addressing the lack of services in 1985 by creating the Missouri Head Injury Advisory Council on March 5, 1985, upon the recommendation of the Joint Interim Committee on Head Injury, a joint legislative committee which held statewide hearings in 1984 and issued a report January 1985. Also at the recommendation of the Joint Interim Committee, the state appropriated some state funding specifically for head injury services.

An appropriation was made in the supplemental appropriation bill in Fiscal Year 1985 to the Office of the Administration for staff and necessary expenses for the council, which was charged with the responsibility of studying and making recommendations for improving services for persons with head injury. The council was administratively assigned to the Office of Administration as the problems and service needs associated with head injury crosses several agencies, yet no state agency has primary responsibility for providing services. The Office of Administration provides a forum for the different state agencies along with consumers, parents and other professionals to coordinate and to plan for state services.

State Head Injury Programs

For Fiscal Year 1986 appropriations were made to the Department of Health for head injury services. The Missouri Chest Hospital, a department facility, was changed to the Missouri Rehabilitation Center. A head injury unit was established representing the first state operated program created specifically for survivors of head injury. State funds were also appropriated to the department to purchase services for persons with head injury. (The appropriation was transferred to the Office of Administration, Division of General Services, July 1, 1987, in order to coordi-

nate services with the service recommendations of the council.)

Role of State Agencies

State departments, other than the Department of Health, which offer programs or services which persons with head injury may be eligible for include: Department of Elementary Secondary Education, Division of Special Education (special education and the sheltered workshop program), Division of Vocational Rehabilitation (general rehabilitation, personal care assistance program and supported work program); Department of Social Services, Division of Family Services (Medicaid eligibility determination and determination for other entitlement programs), Division of Medical Services; and Department of Mental Health, Division of Mental Retardation-Developmental Disabilities and the Division of Comprehensive Psychiatric Services. There are also several local and private agencies which contract with the state departments to provide a variety of services. The Department of Public Safety through the State Highway Patrol and the Division of Highway Safety promotes highway safety in order to prevent and reduce fatalities and injuries.

In general, it has been difficult for persons with head injury to access the various state/federally funded programs due to eligibility criteria. Many of the programs offer services based on financial eligibility and others offer services to special populations groups which do not include head injury.

Many fields use a case management system to coordinate and monitor all services to meet the full range of needs of an individual client. Case management can include the following general functions: (1) outreach, (2) intake, (3) assessment, (4) service plan development, (5) service coordination, (6) advocacy, (7) crisis intervention and (8) monitoring. The purpose of case management is to ensure that clients receive appropriate services.

Although some head injury programs, medical programs, insurance, mental health, vocational rehabilitation and others use a case management service within their own programs, there is not a statewide case management system independent of providers for survivors of head injury. Such a system would allow for coordination of services which may be provided by different agencies.

Accomplishments

The council has conducted and continues to be involved with projects to identify the extent of head injury, services needed, services available and to coordinate and maximize existing services available for other disability populations. The council provided assistance to the Department of Health and the Office of Administration, Division of Purchasing, in developing Request for Proposals for the head injury service appropriation awarded to the department for FY'86. (For FY'86, \$500,000 was appropriated.) The council viewed the process as an opportunity for providers to develop innovative approaches for services. During this process, it was noted by the council that there was a lack of common terminology for programs and services and differing perceptions as to how services should be provided.

Definitions

To assist with program planning and development the Missouri Head Injury Advisory Council first defined head injury and services which may be needed. At that time (fall 1986), the National Head Injury Foundation had not developed a definition for head injury. After reviewing definitions used by some states, the council defined the term "head injury". This definition was included in the legislation establishing the head injury register and the council, which passed in the 1986 legislative session. The definition is used for request for proposals for head injury services issued by the Missouri Division of Purchasing for the Office of Administration, Division of General Services.

Also during FY'86, the council identified and defined services and programs which may be needed starting with acute brain injury rehabilitation, functional living rehabilitation, transitional living, residential, case management and community support services. The report, *Proposed Service Delivery System for Rehabilitation of Missourians with Head Injury*, was distributed statewide for comment. For FY'88 head injury contracts, these definitions were incorporated in the Request for Proposals.

During FY'87, the council through its committees, developed its *Action Plan* containing goals and objectives for developing and improving services. This plan was included in the FY'87 *Annual Report* and became the guide for its activities. The goals and objectives are now a part of each annual report.

Also during FY'86, the council conducted a survey to

determine how many persons with head injury have sought services from the Department of Mental Health facilities and community programs as well as from nursing homes and home health care agencies. The report, *Survey of Missourians with Severe Head Injury Served by Mental Health, Home Health & Nursing Home Facilities*, indicated that persons are being served to some degree. Most of the persons receive maintenance services, but few receive specific treatments directed at brain injury induced deficits. Over half of the persons surveyed will still need services in five years. The lack of a state statutory definition at that time presented some limitations. To be eligible for services by the Missouri Department of Mental Health, Division of Comprehensive Psychiatric Services or the Division of Mental Retardation and Developmental Disabilities, persons must fit the definition of mentally ill, mental retardation, or developmentally disabled and require the services offered by the department. Persons admitted or placed by the department are usually diagnosed accordingly.

Public Hearing

On January 19, 1988, the council co-sponsored with the Office of Administration, Division of General Services, a public hearing to obtain recommendations for service priorities for the appropriation to the division for head injury services. Also, the division, upon the recommendation of the council, entered into a contract with the University of Missouri-Columbia, School of Journalism, Bureau of Media Research, to conduct a statewide poll to determine public awareness of head injury and the prevalence of head injury. The council developed the questionnaire and the University conducted completed the report in the fall of 1988.

State Funded Programs

The council supported funding for additional staff for FY'87 for a head injury unit at St. Louis State Hospital. (The facility had previously identified patients believed to be head injured and who exhibited aggressive behavior in an attempt to provide more appropriate services.) The council believes that the Department of Mental Health has a role in treating persons with head injury who also exhibit severe and aggressive behavior problems. It has encouraged the department and the Department of Health, Missouri Rehabilitation Center, to develop an inter-agency agreement in order to coordinate services between the two facilities. For FY'90 the Department of Mental Health, Division of Comprehensive Psychiatric Services has included in its state mental health

plan recommendations from the council with regard to the role of the division in serving clients with head injury.

The council has also advocated for additional funds to expand the head injury unit at Missouri Rehabilitation since its creation in FY'86 and to expand community services under contract with the Office of Administration. The appropriation for FY'87 for head injury services (contractual) was reduced to \$272,000 and for FY'88 was increased to \$314,685 (and was transferred to the Office of Administration, Division of General Services) and remained at the FY'88 level for FY'89. For FY'90, the appropriation has been increased to \$521,685.

The Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, agreed to include some of its eligible clients or potential clients of the division who are disabled as

the result of a head injury under the Medicaid Waiver approved by the federal government for implementation beginning July 1988. The three-year waiver allows federal Medicaid reimbursement for nine home- and community-based services for eligible clients of the Department of Mental Health with developmental disabilities. The waiver is to initially be implemented in certain counties in five service catchment areas. The division has requested the regional centers for the developmentally disabled to identify clients with head injury who may be eligible under the waiver.

The council chairman appointed a Task Force on Service Delivery Systems Recommendations May 1988 to study and to recommend which agency should have primary responsibility for serving persons with head injury. The Task Force recommended that the Department of Health should have primary responsibility for developing and providing services to survivors of head injury.

Plan Initiatives

Three-Year Goal: To assess service needs of survivors of head injury.

Assess Service Needs

First-Year Objectives

Fiscal Year 1989

1. Rank service needs based on council knowledge and/or in consultation with other organizations.
2. To develop or to assist others to develop a tool or method to assess service needs comprehensively.
3. To develop an inventory of services currently provided.

Progress in Meeting FY'89 Objectives: In order to develop a service inventory/directory a survey was sent to known head injury providers, nursing homes and hospitals during FY'89. The directory has not yet been published. A client/patient profile form was developed by council staff for head injury programs under contract with the Office of Administration, Division of General Services to complete in order to make some determination as to the average age, sex, length of time between acute care and the programs services, services needed following discharge, etc. The form will be distributed for FY'90.

Roles of State Agencies

Second-Year Objectives

Fiscal Year 1990

1. To continue comprehensive assessment of needs.
2. Work with the Department of Health to develop research projects for purposes of assessing needs utilizing registry data.
3. Work with the Missouri Rehabilitation Center to determine the type of services patients discharged from the Center will need in order to return to the community.

Progress In Meeting FY'90 Objectives: The Department of Health with support from the council has received a contract from the National Highway Traffic Safety Administration to follow a selected group of patients with head injury after hospital discharge to assess service needs.

Third-Year Objectives

Fiscal Year 1991

1. To continue or to support research projects.
2. To rank service needs by service catchment area based on survey results, current services provided and data from head injury registry.

Three-Year Goal: To determine roles of existing state agencies in providing directly or indirectly services to survivors of head injury and their families.

Second-Year Objectives

Fiscal Year 1990

1. To develop agreements as to how services are to be provided and alternatives for departments when the department's services are not appropriate.
2. To develop a referral system for state agencies and non-state agencies.

Third-Year Objectives

Fiscal Year 1991

1. To determine which, if just one, state agency should have primary program responsibility for survivors of head injury.

Progress In Meeting FY'89-91 Objectives: The council has encouraged the Department of Health, Missouri Rehabilitation Center, and the Department of Mental Health, St. Louis State Hospital, to develop an interagency agreement so as to coordinate services. The departments are in the process of developing an agreement. The Department of Mental Health, Division of Comprehensive Psychiatric Services solicited input from the council as to the role of the division in providing services for inclusion in the state mental health plan. The council

recommended to the Missouri Planning Council on Developmental Disabilities that the state definition for developmental disability be changed to the federal definition. The council chairman appointed a Task Force on Service Delivery Systems Recommendations to study and to recommend which agency should have primary responsibility for serving persons with head injury.

Four-Year Goal: To develop a case management model system.

**First- through Fourth-Year
Objectives**

**Fiscal Years 1989-
1992**

1. To work with the Department of Mental Health to establish a pilot project under the Medicaid waiver.
2. To develop budget requests for case managers based on the council's study.

Progress In Meeting FY'89-92 Objectives: The Task Force on Service Delivery Systems recommended that a division of head injury and rehabilitation be created in the Department of Health with case management as a central part of the service system. The Office of Administration did not recommend a FY'90 budget request for a case manager for the head injury program.

Case Management

Issue 3: Rehabilitation Services

Background

Part of the challenge of providing adequate care for persons who sustain traumatic head injury is the diversity of needs after injury. Post-injury can range from full time care to community re-integration. The order in which services are used can also vary; some people will move from acute medical care into community integration while others may require extended periods of nursing care before they benefit from rehabilitation. Many persons require more than one type of treatment simultaneously. Thus, services must be flexible, but also allow for the most frequent progressions.

Most often, after traumatic brain injury, the survivor goes from acute medical care to rehabilitation. This first rehabilitation, or *Acute Brain Injury Rehabilitation*, focuses on physical and gross cognitive deficits. This intensive rehabilitation program provides com-

prehensive goal directed rehabilitation services. The program is designed to prevent and/or minimize chronic disabilities while restoring the individual to the optimal level of physical, cognitive, and behavioral function. The rehabilitation program should be carefully coordinated and implemented as soon after onset of injury as is medically feasible.

Functional Living Rehabilitation provides intensive rehabilitation with goal directed services to persons who have either completed acute rehabilitation or who have no major acute rehabilitation needs. Emphasis on this program is on functional cognitive, memory, or perceptual deficits, and appropriate interpersonal skills. Speech and language therapy, occupational and/or physical therapy are usually provided. Services may be delivered on an inpatient (residential) or outpatient (day program) basis.

Transitional Living Rehabilitation programs provide

intensive rehabilitation with goal directed services to persons who have sustained traumatic head injury and who have completed acute and functional living rehabilitation programs or who have no significant need for those services. Emphasis in this program is on living in an independent situation. In this program, participants would typically move from close observation and supervision to independent living with minimal supervision. Transitional living programs may exist independently or may be part of a larger program. The program should provide safe, accessible housing which allows transition from group living situations to independent living.

Rehabilitation programs for persons with head injury are relatively new. Private programs have developed across the country over the past ten years, usually focusing on coma management, functional living rehabilitation, and/or transitional living programs. A few companies have begun developing supervised living programs. These programs generally rely on patients/clients who have the ability to pay. In some states, head injury programs have been able to be reimbursed under the state's Medicaid program for certain services. For those persons who do not have the ability to pay, whose insurance will not cover the services, whose insurance has been exhausted, or do not have any other source such as Workers' Compensation, rehabilitation services are extremely limited.

Many persons who suffer from a head injury may return to employment. Others, with vocational or pre-vocational rehabilitation—which may be in addition to rehabilitation as described above, may return to employment. Still, others will need either supported employment or sheltered employment or day programs after rehabilitation. Day activity programs in this sense would maintain the intellectual, emotional, social, vocational and physical capacity of persons who are not able to maintain any type of employment. The program has a different purpose than a day treatment (functional living rehabilitation or transitional living) program.

In Missouri, the state provides some rehabilitation services through the Missouri Rehabilitation Center and through state contracts with the Office of Administration. In addition, The Missouri Department of Elementary and Secondary Education, Division of Vocational Rehabilitation, provides vocational rehabilitation services for those persons who may be determined to be employable. For those persons who are not quite ready for vocational rehabilitation and do not need the intense level of rehabilitation provided in functional living rehabilitation, pre-voca-

tional training or work readiness may be needed. There are at least two programs which fit in this category: Blue Valley Industries, Kansas City, which contracts with the Division of Vocational Rehabilitation, and Advent Enterprises, Inc., Columbia, which is under contract with the Office of Administration to provide pre-vocational services. A day program was established in St. Louis by the Bi-State Chapter of the Missouri Head Injury Association and is under contract with the Office of Administration.

As the result of federal legislation, the Missouri Division of Vocational Rehabilitation administers the supported work program. Most persons with head injury have been unable in the past to access the supported work program due to lack of long term support services which are necessary in order to participate in the federal program.

Accomplishments

During FY'86, the council defined rehabilitation programs in terms of program setting, staffing and treatment/rehabilitation considerations. A report was prepared and circulated statewide for comment. The definitions were incorporated in the Request for Proposal document issued by the Missouri Office of Administration, Division of Purchasing, soliciting proposals for contracts for head injury services.

Vocational Rehabilitation

The Division of Vocational Rehabilitation has assigned a vocational rehabilitation counselor in each district office to work with clients with head injuries. The division provides ongoing in-service training regarding head injury to counselors. Part of the in-service training has included sending counselors and central office staff to the annual conferences sponsored by the council. Some of the division staff have assisted with presentations and with making suggestions for workshop topics.

The Missouri Head Injury Advisory Council initiated legislation introduced during the 1987 legislative session to allow sheltered workshops to receive a portion of the state subsidy for those clients who work less than six hours a day. This was introduced and passed to give the workshop staff flexibility to tailor the workshop program for those who may not be able to work a six hour day or who may require programming in conjunction with part time sheltered employment. Blue Valley Industries, Kansas City, has

opened a pre-vocational program and a sheltered workshop program for persons with head injury. However, the Division of Special Education has refused to certify the program as a sheltered workshop under 178.900 RSMo as the division has operated under a rule which does not allow a sheltered workshop to be established to employ only one disability.

The Office of Administration, Division of General Services, contracts with Advent Enterprises, Inc., Columbia, for pre-vocational services and with Truman Center-East and Rusk Rehabilitation Center for functional living rehabilitation services. A day activity program was established in St. Louis by the Bi-State Chapter of the Missouri Head Injury Association with

funding from the head injury services contractual appropriation which is administered by the Office of Administration, Division of General Services. The program serves ten clients.

The Missouri General Assembly appropriated \$207,000 to the Office of Administration, Division of General Services for FY'90 for long-term support services to enable persons with head injury to participate in the federal supported work program initially funded by the Division of Vocational Rehabilitation. Requests for Proposals were issued in May 1989.

The state Medicaid program was expanded in 1988 to cover functional living rehabilitation (Medicaid term used is "comprehensive day rehabilitation").

Plan Initiatives

Four-Year Goal: To develop an array of head injury rehabilitation programs accessible statewide.

Rehabilitation Programs

First-Year Objectives

Fiscal Year 1989

1. To include in the service inventory the number, location, eligibility requirements and type of rehabilitation programs currently available statewide.
2. To address rehabilitation programs in the needs assessment survey.
3. Determine the need for rehabilitation programs based on needs assessment survey, service inventory and trauma registry.

Progress in Meeting FY'89 Objectives: During FY'89, surveys were sent to providers and other organizations to determine the extent services are being provided and if services are being planned for the future. The survey included requests for information with regard to service catchment area, eligibility criteria, and methods for payment. That information has yet to be compiled.

First- through Fourth-Year Objectives

Fiscal Years 1989-1992

1. Continue to determine the need for rehabilitation programs based on needs assessment survey, service inventory and trauma registry.

Program Coordination

2. Prepare and submit budget request to establish a transitional living (residential) program.
3. Support expansion of the head injury programs, including the transitional living programs, at the Missouri Rehabilitation Center, Mt. Vernon.
4. Prepare and submit budget requests for other rehabilitation programs based on needs assessment.

Progress in Meeting FY'89-92 Objectives: Council members testified before the Missouri Board of Health and the Missouri Department of Health regarding the need for expanding the Missouri Rehabilitation Center. The council also testified before the Missouri House of Representatives Appropriation Committee on Mental Health and Health with regard to the Missouri Rehabilitation Center. The Office of Administration, Division of General Services submitted budget requests to expand services to include transitional living and supported work programs (long-term support). The budget item for long-term support in conjunction with supported employment was approved.

Two-Year Goal: To promote coordination between acute hospitals and acute brain injury rehabilitation programs and between acute brain injury rehabilitation programs, functional living, transitional living programs and community support programs.

First- through Second-Year Objectives

Fiscal Years 1989-
1990

1. Distribute information regarding availability of services compiled as the result of the service inventory to social services department of hospitals.
2. Require programs receiving state funding from the Missouri Office of Administration, Division of General Services to have written agreements and/or policy regarding the relationships between the facility and rehabilitation programs, community support programs, acute hospitals and/or educational programs. The programs should be able to document the results of the agreements.
3. Conduct workshops regarding availability of services.
4. Promote awareness of programs through newsletter.

Progress in Meeting FY'89-90 Objectives: The Request for Proposals for head injury services require contractors to have written agreements between the facility and various programs. The council has encouraged the Department of Mental Health and the Department of Health to develop an interagency agreement with regard to St. Louis State Hospital and Missouri Rehabilitation Center. The council newsletter, *Quarterly*, features head injury programs and services,

both private and state programs. During the annual conference, 26 exhibitors displayed information pertaining to their programs and several program providers presented during the conference. Council staff made presentations regarding services to the Missouri Head Injury Association Board of Directors on a regular basis, during the Association's annual conference, Missouri Association of Rehabilitation Facilities, St. Louis Mental Health Association, Missouri Association of County Developmental Disabilities Services, Missouri Coalition of Community Mental Health Centers and Missouri Planning Council for Developmental Disabilities.

Three-Year Goal: To develop programs which offer pre-vocational, vocational and/or vocational rehabilitation services.

Vocational Rehabilitation

First- through Third-Year Objectives

Fiscal Years 1989-1991

1. To encourage private/public institutions to develop vocational training programs for survivors of head injury.
2. Draft legislation, if needed, to allow state subsidy for those sheltered workshops who opt to provide training in addition to sheltered employment.
3. To determine the role of vocational education schools in providing vocational training to students who have suffered from a head injury.

Three-Year Goal: Develop sheltered employment for employees who are handicapped due to head injury.

Sheltered Employment

First- through Third-Year Objectives

Fiscal Years 1989-1991

1. Encourage the establishment of sheltered employment for persons with head injury.

Progress In Meeting FY'89-91 Objectives: During FY'88, Council staff served on the sheltered workshop advisory committee established by the Division of Special Education. The sheltered workshop managers suggested that the council develop a "white paper" outlining how the council believed sheltered employment should be made available to persons with head injury (setting, staffing, type of work, separate facilities, etc.). The council Committee on Program Planning and Development reviewed the types of sheltered employment (benchwork model, enclave, mobile crew, etc.) and made some preliminary recommendations which have not yet been drafted for a paper.

Supported Work

One-Year Goal: To develop supported work programs.

First-Year Objectives

Fiscal Year 1989

1. Review the Division of Vocational Rehabilitation and other agencies plan for a supported employment initiative.
2. Survey the number of head injured who would benefit from supported work programs.
3. Participate with the Division of Special Education in determining the sheltered workshops' role, if any, in providing supported employment programs.

Progress in Meeting FY'89 Objectives: During the summer of 1988, council staff met with the Governor's Core Policy Team on Supported Employment and the Team agreed that supported work would be beneficial to persons with head injury. Persons with head injury have been unable to access the supported work program as one of the federal requirements is that long-term support must be available. The Team wrote a letter supporting a budget request for the Office of Administration, Division of General Services, for long-term support programs to enable persons with head injury to participate in the supported work program. The Division of Vocational Rehabilitation estimates that at least 30 clients could be served the first year. The Office of Administration, Division of General Services submitted a budget request which was agreed to by the Missouri General Assembly. A Request for Proposals for long-term support providers was issued in the spring of 1989.

Second-Year Objectives

Fiscal Year 1990

1. Draft legislation, if needed, to address supported employment.
2. Work with the Division of Vocational Rehabilitation in accessing VR funds for supported employment for head injured clients.
3. Encourage the development of supported work programs.

Three-Year Goal: To develop employment opportunities.

First- through Third-Year Objectives

Fiscal Years 1990-1992

1. To determine vocational training and skills needed in order for survivors of head injury to become employable.
2. To evaluate success of persons with head injury in returning to employment.

Competitive Employment

3. To recognize employers who have established exemplary programs for employing persons with head injury.
4. To develop informational brochures for employers regarding the benefits of hiring persons handicapped due to head injuries.

Five-Year Goal: To establish day activity programs.

**First- through Fifth-Year
Objectives**

Fiscal Years 1990-1994

**Day Activity
Programs**

1. Survey number of existing day programs or planned programs to be included in the service inventory/directory.
2. Determine need according to needs assessment.
3. Develop a model for day activity programs which address:
 - (a) a definition/description of day activity programs including the qualifications of day program providers paid under state contract.
 - (b) an array of day program services which should be available according to needs assessment and registry data.
4. Explore funding for adult day care.
5. Work with the Department of Mental Health to develop day care, personal care, respite and home/equipment modification under the Medicaid waiver.
6. Prepare and submit budget requests to expand day programs and other support services.

Progress In Meeting FY'90 Objectives: A budget request was submitted for FY'90 for support services (community re-entry).

Issue 4: Services for Children

Background

Rehabilitation services for children are limited. Very few services are available to children with long-term medical needs. However, legislation which passed during the 1988 legislative session allows for the establishment of nursing homes for children under the state Medicaid program. The legislation also

expands Medicaid eligibility for children. Also under a Medicaid Waiver, some in-home services are available for children with acute medical needs.

The Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, provides some services to children with head injuries and their families. The division considers a child to be developmentally disabled when the injury

occurs prior to age 18 and the child functions similarly to those children with mental retardation or other developmental disabilities. The division may offer case management and respite services for children who qualify, however, the division is reluctant to pay for medical or rehabilitation services associated with injury or to provide counseling or other family support services.

The Bureau of Special Needs, formerly the Crippled Children's Services, pays for some rehabilitation, however, the program will not cover services of a psychologists or cognitive re-training.

Accomplishments

The Missouri Department of Elementary and Secondary Education, Division of Special Education, has assigned staff to assist school districts to provide educational services to children with head injuries. The division has prepared a manual, *Developing*

Individual Education Plans for Students Who Have Suffered Traumatic Head Injury, to be used in conjunction with the educator's manual prepared by the National Head Injury Foundation. The Missouri Division of Special Education has made the National Head Injury Foundation manual available to teachers upon request and encourages special educators to use the division's manual as a supplement. Films and other materials on head injury have been added to the Special Education Dissemination Center, University of Missouri-Columbia, a resource center for teachers and school administrators in Missouri who serve handicapped children.

The Department of Mental Health received approval for a Medicaid waiver which will allow reimbursement under the Medicaid program for community services for eligible or potential clients of the Division of Mental Retardation and Developmental Disabilities—including those who meet the division's eligibility requirements as the result of head injury. The waiver will include all ages provided they can also meet Medicaid eligibility.

Plan Initiatives

Four-Year Goal: To study and recommend appropriate rehabilitation, long-term care, educational, respite and other support services for children with head injuries and their families.

Model Services for Children

First- through Four-Year Objectives

Fiscal Years 1989-1992

1. Study and recommend a model(s) for programs for children suffering from head injury.
2. Work with the Department of Mental Health, Department of Elementary and Secondary Education and Department of Health to determine their roles in providing services to children with head injuries.
3. Work with the state agencies to determine the number of school age children with head injuries.

Progress in Meeting FY'89 Objectives: The council continues to work with the Department of Mental to determine its role and with the Department of Elementary and Secondary Education, Division of Special Education, on how to transition children from acute/rehabilitation facilities to school programs.

Issue 5: Residential Services

Background

The goal of rehabilitation is to enable a person to return to his or her environment and to live as independently as possible. For those who are unable to live independently either within the family structure or alone, then some type of housing or support which provides supervision and protection may be needed.

Others may require continued rehabilitation, medical, or specialized care provided in a residential setting. Residential settings which may be needed include nursing facilities, structured residential placement for those exhibiting severe behavior problems and supervised living arrangements.

In-Home Assistance, Respite Care

For others to live independently some assistance may be required such as personal care assistance, in-home support, or home health care assistance. A family may need the benefit of respite care in order to maintain a family member with a head injury at home. Respite care provides temporary relief or emergency relief to the family.

If a person with a head injury meets the state definition for developmental disability (injury occurs before the age 18), then the family may be eligible for respite care services from one of the eleven regional centers for the developmentally disabled operated by the Department of Mental Health, Division of Mental Retardation and Developmental Disabilities.

Long-Term Care/Housing

Long-term housing has yet to be developed specifically for survivors of head injury. Some individuals with head injury have been placed in community based residential facilities for persons with developmental disabilities, habilitation centers and hospitals operated by the Department of Mental Health or in nursing homes. However, the Division of Mental Retardation and Developmental Disabilities has implemented the policy of placing only persons with mental retardation in community residential homes.

Accomplishments

During the FY'86, the Missouri Head Injury Advisory Council surveyed the number of survivors of head injury receiving services from the Department of

Mental Health through its Divisions of Comprehensive Psychiatric Services and Mental Retardation and Developmental Disabilities, nursing homes and from home health care agencies. The survey noted that a significant number were being served, although most were not receiving services specific to their injury related deficits.

MR-DD Medicaid Waiver

The Department of Mental Health is proposing to include eligible head injury clients receiving services from the Division of Mental Retardation and Developmental Disabilities under a Medicaid waiver in an attempt to provide services more appropriately and in a less restrictive environment. Services proposed under the waiver include residential, respite, and home adaptation.

Behavior Programs

St. Louis State Hospital, a psychiatric facility operated by the Department of Mental Health, has established a unit for persons with head injury who also have severe behavior problems. The council has supported funding for the unit and has encourage the department to coordinate services with the Missouri Rehabilitation Center operated by the Department of Health. The Missouri Rehabilitation Center received funding for four beds for severe behavior during the 1989 legislative session.

Some nursing facilities have expressed interest in serving head injured persons who are comatose, semi-comatose or who have extensive medical needs, however, the state Medicaid reimbursement rate does not accommodate the costs of serving such persons

In-Home Support Services

The Office of Administration, Division of General Services, contracts with Services for Independent Living, Inc., an independent living center in Columbia for in-home support services.

The Missouri Association of Head Injury sponsors Wilderness Retreat at the Lake of the Ozarks during the summer with funds, in part, from the Office of Administration. The Retreat not only provides socialization/recreational opportunities for survivors of head injury, but also respite for their families.

**Department of
Mental Health
Medicaid Waiver**

Plan Initiatives

Two-Year Goal: Participate with the Department of Mental Health to obtain a Medicaid waiver and to implement the waiver, should it be approved.

First-Year Objectives

Fiscal Year 1989

1. Assist the department in determining clients or potential clients with head injury who would be more appropriately served under the waiver.
2. Assist the Department of Mental Health in identifying potential provider for services approved in the Medicaid waiver.
3. Assist the Division of Mental Retardation and Developmental Disabilities with the development of policy with regard to appropriate services for those clients who have suffered a head injury.

Progress in Meeting FY'89 Objectives: Staff from the Department of Mental Health, Division of Mental Retardation and Developmental Disabilities directed the regional centers to identify the persons with head injury who may be eligible under the Medicaid Waiver. The division scheduled meetings throughout the state in the fall to discuss the waiver.

Second-Year Objectives

Fiscal Year 1990

1. Assist the Division of Mental Retardation and Developmental Disabilities by providing/arranging training to case managers with regard to evaluation/assessment, interpretation, and writing appropriate rehabilitation/treatment goals.

Two Year Goal: To develop coma and semi-coma management programs.

**Coma, Semi-Coma
Management
Programs**

First-Year Objectives

Fiscal Year 1989

1. Survey and/or use registry data to determine the number of persons requiring coma/semi-coma care.
2. Support the Missouri Rehabilitation Center in developing either a coma or semi-coma management program.
3. Initiate a committee or task force to study the costs of coma management programs.

4. The committee once appointed, will study the necessary staffing and medical/equipment considerations for a coma management program.
5. The committee will look at existing rate structure under the Medicaid program, the Medicaid exception process, Medicaid waiver or other funding areas and make recommendations as to how coma/semi-coma management programs should be funded.

Progress in Meeting FY'89 Objectives: Members of the council presented testimony to the Missouri Board of Health and before the House Appropriations Committee on Mental Health and Health supporting a semi-coma management program at the Missouri Rehabilitation Center. During the 1988 legislative session a house resolution passed calling for a joint interim committee to study nursing shortage and the Senate appointed an interim committee to study nursing home issues. The council followed the hearings of both of these committees which met during the fall of 1988, and arranged testimony to address the lack of nursing facilities to provide care and rehabilitation for coma, semi-coma or persons who require intensive medical and rehabilitative care. Legislation was introduced during the 1989 session to address the situation and the legislation did not pass.

Second-Year Objectives

Fiscal Year 1990

1. Introduce legislation, if needed, to implement coma/semi-coma management or other medically/rehabilitative intensive programs.
2. Develop standards, if needed, for the above programs.
3. Working with nursing home organizations, assist with staff training, if desired.

**Behavior
Management
Programs**

Three-Year Goal: To develop behavior management programs.

First-Year Objectives

Fiscal Year 1989

1. Determine the need for a structured residential placement to be developed specifically for those with severe behavior problems.
2. Identify program costs needed for a program for severe behavior disorders.

Progress in Meeting FY'89 Objectives: The council supported the Department of Health budget item for the Missouri Rehabilitation Center for four bed for severe behavior disorders.

Second-Year Objectives

Fiscal Year 1990

1. Identify eligibility criteria for behavior management programs.

Supervised Living Arrangements

2. Identify potential providers for a behavior management programs.
3. Work with the University of Missouri-Columbia to develop in-service staff training workshop(s) designed to assist program (state and non-state) staff in managing aggressive behavior exhibited by head injured clients.

Third-Year Objectives

Fiscal Year 1991

1. Prepare and submit a budget request to increase state funding for a pilot behavior management program.

Five-Year Goal: To develop supervised living arrangements for those who will continue to need supervision following rehabilitation.

First- and Second-Year Objectives

Fiscal Years 1989-1990

1. To develop a model for supervised living arrangements addressing:
 - (a) a definition/description of supervised living arrangements (apartment, group home), including staff requirements or other requirements.
 - (b) an array of support services, including day programs or employment needed in conjunction with supervised living arrangements.
 - (c) standards, including physical plant facility, safety, drugs and medications, record keeping and client rights.
2. To study similar residential alternatives available to persons with head injury in other states and similar programs offered to other population groups in Missouri.
3. Determine the number of persons with head injury who are in need of supervised residential programs.

Progress in Meeting FY'89 Objectives: This project has not been undertaken.

Third-Year Objectives

Fiscal Year 1991

1. Study and recommend how supervised living arrangements could be funded, both start up costs and operational costs.
2. Conduct a workshop on funding sources (HUD, Section 8, "S.B. 40", insurance and other sources) for supervised living arrangements.

**Third- through Fifth-Year
Objectives**

**Fiscal Years 1990-
1993**

1. Locate potential providers for developing supervised living arrangements.
2. Assist potential providers in accessing funds.
3. Prepare and submit budget request to assist with funding for supervised residential programs.

Three-Year Goal: To expand usage of home health care and personal care attendant services.

In-Home Support

First-Year Objective

Fiscal Year 1989

1. To work with the Department of Mental Health to identify vendors who could provide home health care under the Medicaid waiver to clients with head injury should the waiver be approved.

Progress in Meeting FY'89 Objective: This objective has yet to be met.

Second-Year Objectives

Fiscal Year 1990

1. To work with the Division of Vocational Rehabilitation to determine the number of persons with head injury who would be eligible for personal care assistance.
2. To work with the Division of Aging to determine how survivors of head injuries and their families could access home health care services through the division's programs.
3. Ask Missouri Association of Home Health Care Agencies and Hospital Home Health Council to include a session on the needs of persons with head injuries and their families at their annual conferences.

**Personal Care
Assistance**

Progress in Meeting FY'89 Objectives: The council staff responded to a call for presentations for the 1988 conference held by the Missouri Association of Home Health Care Agencies offering to present along with staff from the University of Missouri-Columbia a workshop on head injury. The Association rejected the presentation proposal.

Third-Year Objectives

Fiscal Year 1991

1. Based on needs on survivors of head injury for personal care assistance, work with the Division of Vocational Rehabilitation to obtain sufficient funding.

Respite Care

2. To develop a referral mechanism or resource document to include home health care agencies which could provide services to survivors of head injury and their families for hospitals, local health units, and physicians.

Three-Year Goal: To develop respite care.

First- through Third-Year Objectives

Fiscal Years 1989-1992

1. To study various methods for providing respite care.
2. To study funding sources for respite care.
3. To develop a model for providing respite care.
4. To encourage providers to offer respite programs.

Five-Year Goal: To develop an array of family support services.

Family Support Services

First- through Fifth-Year Objectives

Fiscal Years 1989-1993

1. To design an array of family support services to include, but not limited to, information and referral, counseling, evaluation, crisis stabilization, in-home rehabilitation, recreation and transportation.
2. To identify potential providers for various family support services.

Issue 6: Professional Training/Staff Development

Background

The demand for professionals experienced in working with survivors of head injury and their families will increase as programs and services are developed. Professionals will be needed in all areas including evaluation, case management, counseling, rehabilitation, community support programs and specialized programs such as behavior and coma management.

The Missouri Head Injury Advisory Council; Missouri Head Injury Association; Rehabilitation Institute, Kansas City; University of Missouri Health Sciences Continuing Education, Columbia; University of Mis-

souri Rehabilitation Continuing Education Program and others have over the past few years sponsored statewide conferences for professionals and parents.

Accomplishments

The Missouri Head Injury Advisory Council has sponsored four statewide conferences which included sessions designed for professionals as well as families and other interested persons. The Division of Vocational Rehabilitation specifically requested sessions for the division's counselors on neuropsychological evaluation and how to interpret

the data to formulate employment goals during the 1987 annual conference sponsored by the council. The division has conducted several seminars for its counselors relating to head injury. The council, Division of Vocational Education and University of Missouri Rehabilitation Continuing Education Program have planned an in-service training workshop for vocational rehabilitation counselors, supported work and long-term support providers for October 1989. The Division of Special Education has assigned staff

to work with school districts and teachers who have students with head injury. The division provides assistance to help teachers to develop appropriate educational plans based on evaluations. The Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, has agreed to work with the council to schedule an in-service training on evaluation and development of treatment plans for staff from the regional centers on developmental disabilities.

Plan Initiatives

Five-Year Goal: Provide opportunities for professionals to expand knowledge on head injury rehabilitation.

First- Through Fifth-Year Objectives

Fiscal Years 1989-1993

1. Conduct a spring conference to include topics such as research, medical, rehabilitation and community re-entry.
2. Work with the Department of Mental Health to assess in-service needs of mental health and mental retardation and developmental disabilities staff.
3. Conduct an in-service training workshop for vocational rehabilitation specialists, supported work providers and long-term support work providers during FY'90.
4. Support the University of Missouri in efforts to obtain training funds to in-service staff providing services to persons with head injury.

Progress In Meeting FY'89 Objectives: The council held its annual conference May 22-22 in Jefferson City. Approximately 150 persons attended. The council is working with the Division of Vocational Rehabilitation and the University of Missouri Rehabilitation Continuing Education Program to schedule an in-service training workshop on supported work for persons with head injury.

Two-Year Goal: To encourage assessment teams to use functional evaluation tools with neuropsychological and medical assessment.

In-Service Training/ Staff Development

Assessment Tools

Behavior Management Training

First- and Second-Year Objectives

Fiscal Years 1989-
1990

1. To study and recommend the development of an evaluation tool to assess the functioning level of a persons with a head injury.
2. Support in-service training/conference(s) to assist staff on how to assess functional level.

Progress in Meeting FY'89 Objectives: This goal has yet to be realized and the council will continue to work on this goal.

Three-Year Goal: To train staff as to how to manage behavior problems.

First- through Third-Year Objectives

Fiscal Years 1989-
1991

1. To work with the University of Missouri-Columbia and/or other institutions to develop training packages for staff.
2. To conduct in-service workshops on behavior management.

Progress in Meeting FY'89-91 Objectives: During the 1988 annual council conference, two workshops were scheduled on behavior management.

Issue 7: Legal Issues

Background

As treatment, rehabilitation and other services for survivors of head injury are relatively new, many professionals, including the legal community, do not understand the deficits—such as cognitive, memory and judgment—that a survivor of head injury may have. Such deficits may pose problems for head injured persons who are trying to meet the demands of daily living.

Sometimes the rehabilitation and care of a person with a head injury are often determined by the amount the person receives through a settlement related to the accident. It is important, therefore, for those representing the survivor to understand the

rehabilitative and, perhaps, the long-term care needs a person may have as the result of the injury.

Although certain types of disability or illness are addressed by law with regard to criminal actions, disabilities due to head injury are not. Persons considered dangerous to self or others may be involuntarily committed for psychiatric care if they are mentally disordered as defined by law or an alcohol or substance abuser as defined by law. A person suffering from a head injury who exhibits behavior which may be considered dangerous to self or others may be detained involuntarily under the provisions stated above for 96 hours. The mental health commitment law, however, does not pertain to persons who may be dangerous as the result of a

brain injury. They cannot be detained beyond 96-hours unless they are determined to be mentally ill.

Another legal issue is the "right to die" issue. There are some instances where as the result of a severe head injury a person will remain in a vegetative state. Some parents or a spouse face a situation where the person will not regain conscious and is dependent on mechanical devices or feeding tubes to sustain life. Missouri does not have a "right to die" statute. The U.S. Supreme Court has agreed to review a case involving the disconnection of a feeding tube from a person with a head injury who is in a coma at the Missouri Rehabilitation Center.

Finally, some survivors of head injury may need protection or assistance in managing their fiscal affairs and/or personal affairs. It is important that the legal community understands how such protection could be provided under Missouri's Guardian-

ship Code by a guardian or limited guardianship and/or a conservator or partial conservatorship.

Family members and other care givers need to understand the laws, as well, as they pertain to survivors of head injury.

Accomplishments

During the 1987, 1988 and 1989 conferences, "workshops on legal issues were offered. Topics included Missouri's Guardianship Code, involuntary detention and criminal law. The Missouri Bar Association has offered to sponsor a seminar on head injury through its continuing education program. The Missouri Association of Trial Attorneys planned seminars on head injury in Kansas City and St. Louis for attorneys for the fall of 1989.

Plan Initiatives

Two-Year Goal: To develop appropriate programs for those persons suffering from a head injury considered dangerous to self or others.

First- through Second-Year Objectives

Fiscal Years 1989-1990

1. Work with the Division of Comprehensive Psychiatric Services, Department of Mental Health, to determine appropriateness of the commitment statutes and the Department of Mental Health programs to serve persons with head injury considered dangerous to self or others.
2. Determine the number of persons who would require this type of care and protection.
3. Study and make recommendations, if appropriate, regarding involuntary outpatient treatment legislation introduced during the 1987 legislative session.

Progress in Meeting FY'89 Objectives: Staff from the Department of Mental Health, Division of Comprehensive Psychiatric Services have met with the council to discuss in particular the role of St. Louis State Hospital and included head injury in the state mental health plan.

Commitment Law

Four-Year Goal: To propose "right to die" legislation for introduction.

**First- through Fifth-Year
Objectives**

**Fiscal Years 1989-
1994**

1. To study legislation from other state regarding the "right to die" issue.
2. To determine other organizations and professional groups which would also be interested in the "right to die" issue.
3. Draft legislation regarding the "right to die" concept.
4. Participate on the Task Force on Ethical Decision Making in Long-Term Care Facilities established by the Division of Aging.

Progress In Meeting FY'89 Objectives: The council supported legislation which would have allowed a person to designate a person to speak on his or behalf with regard to medical decisions to prolong life in the event the person is unable to make that decision due to his or her medical condition. The legislation failed to make it out of committee. The council staff participated on the Task Force on Ethical Decision Making in Long-Term Care Facilities established by the Division of Aging.

**Seminar for
Attorneys**

Three-Year Goal: To educate the legal system.

**First- through Third-Year
Objectives**

**Fiscal Years 1989-
1991**

1. To ask the Missouri Association of Trial Attorneys to include a session(s) on head injury, at its annual conference.
2. To ask the Missouri Bar Association to include a seminar(s) on head injury through its continuing education program.
3. To ask that head injury be included in the Missouri Judicial Conference.
4. To ask the Missouri Bar or other legal associations to form a committee or task force to discuss and make legislative recommendations with regard to head injury and commitment issues, criminal issues, and other legal issues.

Progress in Meeting FY'88-89 Objectives: The Missouri Bar Association has agreed to sponsor a seminar. The Missouri Association of Trial Attorneys on its own is sponsoring seminars.

Issue 8: Quality Assurance

Background

Since programs for survivors of head injury are relatively new, there are no state licensure or certification requirements for programs serving exclusively persons with head injury. (There are licensure/certification requirements for nursing homes and residential and day programs serving persons with mental illness, alcohol and drug abuse problems, mental retardation or other developmental disabilities.) The Commission on Accreditation of Rehabilitation Facilities (CARF), which is a voluntary organization, has developed accreditation standards for acute rehabilitation programs. The National Head Injury Foundation is an associate member of CARF.

Accomplishments

During FY'86, the council defined acute, functional and transitional living programs based, in part, on CARF standards. These definitions along with some fire and safety standards taken from the Department of Mental Health licensure standards were incorporated in the Request for Proposals issued by the Division of Purchasing and are a part of the contracts the Office of Administration, Division of General Services, have with agencies providing services to persons with head injury. During the 1988 May conference, a featured speaker addressed programs standards and the standards developed by CARF.

Plan Initiatives

Four-Year Goal: To develop standards for head injury programs receiving state funds.

First- through Fourth-Year Objectives

Fiscal Years 1989-
1992

1. Study and make recommendations for program standards with regard to staffing, safety and treatment/ rehabilitation plans,
2. As standards are developed and are accepted, incorporate them into state program contracts (RFPs).

Progress in Meeting FY'89 Objectives: Some program definitions and safety standards were incorporated in the RFPs issued for FY'89. Provisions were made for licensure of state funded programs in the senate bill introduced in the 1989 session which would have established a division of head injury and rehabilitation. The bill did not pass.

Program Standards

Issue 9: Financial Support

Background

Head trauma usually results in large medical bills particularly if the person is hospitalized extensively and/or requires long-term rehabilitation and care. Private insurance pays for at least partial acute care medical expenses. Many policies, however, do not cover rehabilitation, or long-term care. The state Medicaid program has strict financial guidelines which make it difficult for working families to be eligible. The program also is limited as to what services it will reimburse, and is particularly limited in reimbursing outpatient rehabilitation.

The costs associated with medical and long-term care will often place financial hardship on families. Should a person not have insurance or should the insurance not cover all expenses and the persons or family does not qualify for Medicaid, there are limited state aid resources to assist with the medical/long-term care expenses.

State Assistance

Some financial aid is available through Missouri Crippled Children's Services administered by the Missouri Department of Health. The program is to help financially eligible children under 21 obtain medical, rehabilitation and other services. The guidelines are broad enough to accommodate children with head injuries, but program funding is limited. The program has also been reluctant to fund psychological and cognitive rehabilitation.

If a person can meet the eligibility requirements of the Department of Mental Retardation, Division of Mental Retardation and Developmental Disabilities, some services are available through the eleven regional centers for developmental disabilities.

The only state funded programs specifically for persons with head injury are through the Missouri Rehabilitation Center operated by the Department of Mental Health and through contracts with the Office of Administration, Division of General Services.

Insurance

There are three issues surrounding insurance. One

issue is that many persons did not carry health care insurance prior to the injury. Therefore, many persons, particularly young adults, do not have insurance to pay for their medical care. Others may carry insurance, but find that their policies do not cover rehabilitation (outpatient) and/or long term care. A third issue is that some survivors of head injury find that following their accidents, they are unable to find affordable health insurance as they are considered "high risk".

A Missouri House of Representatives committee studied health care issues during the interim in 1986. It recommended a "MedAssist" program to help those who were unable to obtain insurance to have a health care plan. During the 1987 summer interim, a joint legislative committee held hearings to address health care issues and issued a report. Legislation was introduced in the 1988 session again for the third year to establish a health insurance program. The legislation did not pass. A voter referendum also failed.

Also, for at least four years legislation has been introduced to create a "high risk" pool in order for those considered "high risk" to be able to obtain insurance.

State/Federal Funding for Disabilities

There are several programs (federal, state and local) which are targeted, in part, to programs for persons with handicaps or directly to handicapped persons. Such programs include HUD (Housing and Urban Development), Section 8 rental subsidy, SSI, Missouri Elderly and Handicapped Transportation Assistance Program, federal Developmental Disabilities program, Vocational Rehabilitation, supported work program, and county mill tax programs for persons who are or otherwise handicapped or developmentally disabled. Most of these programs have yet to be tapped by persons who are disabled due to a head injury or by programs providing head injury services.

Limited federal funding is available for head injury research, prevention, supported work and rehabilitation. A federal interagency task force met from 1988-1989 and made some funding recommendations.

Accomplishments

Council members testified before the interim house committee on health care regarding the needs of survivors of head injury. The council supported legislation to create a high risk pool and initiated legislation to create a catastrophic fund. During the 1987 session, legislation was introduced to allow voters to increase cigarette taxes to be used for a state catastrophic fund. The proposal failed to receive approval from the senate committee. A Senate Concurrent Resolution No. 6 passed during the 1987 session calling for a joint interim committee to study health care needs. The council staff represented the Office of Administration on the committee which was comprised of five senators, five representatives, public members and state agencies.

Senator Ed Dirck, council member, requested an

Attorney General's opinion as to whether programs providing services to persons with head injuries would be eligible to receive funding from county boards which administer revenue generated from a county tax for persons with handicaps and developmental disabilities. The opinion was that the programs would be eligible. The opinion was sent to all county boards and sheltered workshops. During the 1988 session, Senator Dirck sponsored legislation which would clarify that persons with head injury would be eligible. The bill did not pass and drew opposition from the mental retardation advocates.

Also, during the 1988 session, legislation sponsored by council member Representative Marvin Proffer passed expanding the Medicaid program. The bill expanded services to include comprehensive day rehabilitation for post acute trauma patients, to allow for the establishment of nursing facilities for children and expanded eligibility requirements for children.

Plan Initiatives

One-Year Goal: For survivors of head injury to be able to obtain health care coverage.

First-Year Objective

Fiscal Year 1989

1. To continue to support efforts to create a high risk pool or any other alternative to allow persons considered high risk due to a head injury to obtain health care insurance.

Progress in Meeting FY'89 Objective: The council supported the risk pool legislation.

Three-Year Goal: To extend health insurance coverage.

First-Year Objectives

Fiscal Year 1989

1. To study present required coverage under Missouri law.
2. To study other states' requirements for health care coverage.

Expand Insurance Coverage

Catastrophic Coverage

Progress in Meeting FY'89 Objective: During two council meetings, presentations were made on insurance, one from a medical consultant of a health corporation and one from a head injury program. The council chairman appointed a council member who works for the Division of Insurance to serve as a liaison member on the Missouri Head Injury Association Insurance Task Force. The council staff attended a National Conference on Automobile Insurance Issues at the invitation of the Insurance Information Institute. The conference discussed costs savings measures including prevention and medical management of injuries.

Second-Year Objectives

Fiscal Year 1990

1. To study and to assess cost savings, if any, if coverage were extended to include rehabilitation.
2. To study costs of including long term care coverage in health policies.
3. To study benefits of including catastrophic coverage in health policies.

Third-Year Objectives

Fiscal Year 1991

1. To meet with the insurance industry to discuss rehabilitation coverage.
2. To meet with business associations and organizations to discuss cost and cost benefits, in any, for including rehabilitation coverage in group policies.

Two-Year Goal: To expand Medicaid coverage.

Expand Medicaid Coverage

First- through Second Year Objectives

Fiscal Years 1989-1990

1. To study state and federal options under the Medicaid programs.
2. To make the legislators aware of the needs of survivors of head injury which could be addressed under the Medicaid program.
3. To recommend changes in the Medicaid program in order to meet the medical needs of survivors of head injury.
4. To study the feasibility of obtaining a Medicaid waiver to cover persons who are disabled due to head injuries.
5. To work with the Senate Select Committee on Nursing Home Problems to develop recommendations for developing a rate reimbursement sufficient to cover persons with head injury who have acute medical and rehabilitation needs.

Progress in Meeting FY'89 Objectives: Council staff worked with the Department of Social Services, Division of Medical Services to develop a vendor

manual and eligibility requirements for the new Medicaid service, comprehensive day rehabilitation service, which was added by way of legislation in 1988. Some programs are expected to be able to bill for services starting July 1989.

Two-Year Goal: To access local, state and federal programs for persons with disabilities.

**First- and Second-Year
Objective**

**Fiscal Year 1989-
1989**

1. To make available to organizations, agencies, and persons information regarding various programs through the newsletter, presentations, etc.

Progress In Meeting FY'89 Objectives: The council routinely provides such information via the newsletter, conferences, presentations, etc.

**First- and Second-Year
Objectives**

**Fiscal Years 1989-
1990**

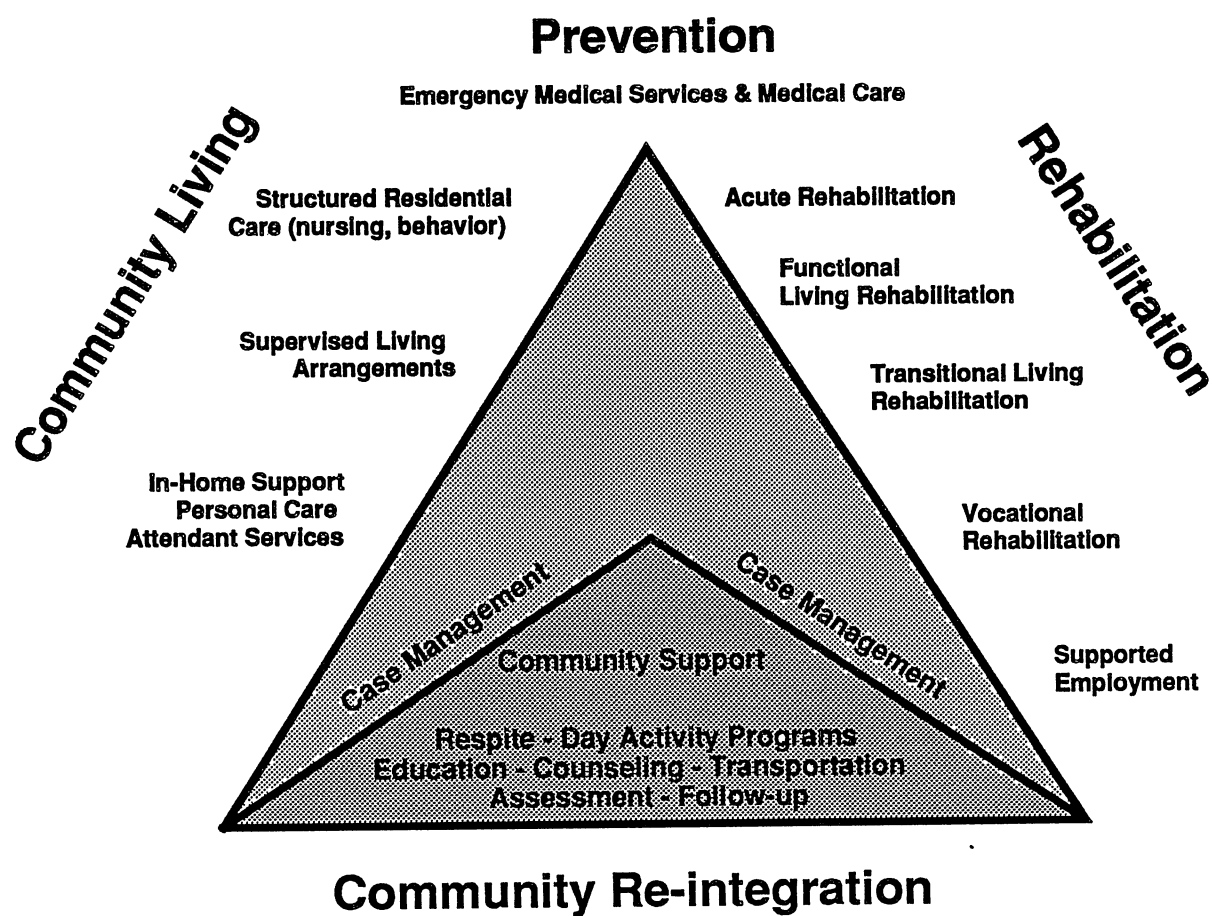
1. To sponsor workshop on funding resources, especially on HUD and Section 8 housing subsidy.
2. To meet with the state Disability Determination office and the Division of Family Services offices to discuss disability due to head injury.
3. Support federal funding for head injury prevention, rehabilitation and long-term care.

Progress In Meeting FY'89 Objectives: The council has worked with and supported the Department of Health and the University of Missouri-Columbia in their pursuit of various grants for prevention and rehabilitation projects. With the exception of the Centers for Disease Control grant the department has been awarded most projects have failed to receive funding. During the council's fifth annual conference held May 1989, a panel representing federal programs presented information regarding programs and funding available through the different agencies.

**Access Local,
State, & Federal
Programs**

Appendix

Service Delivery Model for Missourians with Head Injury



About the Missouri Head Injury Advisory Council

The Missouri Head Injury Advisory Council is to be comprised of twenty-five members of which twenty-one are appointed by the Governor with advice and consent of the Missouri Senate. The twenty-one members represent consumers, families with a member with a head injury, professionals, proprietary schools, private industry, and state agencies which administer education, mental health, health, Medicaid, insurance, vocational rehabilitation and public safety programs. Four members represent

the Missouri General Assembly of which two are state representatives and are appointed by the Speaker of the House of Representatives for the remainder of their terms and two members are state senators appointed by the Senate President Pro-Tempore for the remainder of their terms.

The council members elect a chairman and vice chairman for a term of one year in accordance with the bylaws.

Judith A. Ferguson, Kimberling City, is chairman of the Missouri Head Injury Advisory Council. She is the founder of the Missouri Head Injury Association and is past vice president of State Association Affairs of the National Head Injury Foundation. She is a family member representative on the council having a son who suffered a head injury in 1978.

Representative Shella Lumpe, University City, is vice chairman of the council. She served as a member of the Joint Interim Committee on Head Injury during the summer of 1984. During the 1986 legislative session, she sponsored legislation which created the head and spinal cord injury registry and established the Missouri Head Injury Advisory Council. She serves as vice chairman of the House Committee on Critical Decisions and of the House Elementary and Secondary Education Committee and as a member of the House Ways and Means Committee and Budget Committee.

John F. Allan, Ed.D., Jefferson City, is the Assistant Commissioner (head) of the Division of Special Education, Department of Elementary and Secondary Education. In addition to assisting local school districts with the provision of services to handicapped children, the division is responsible for the state schools for the severely handicapped, state school for the blind, state school for the deaf, and administering the sheltered workshop subsidy. Dr. Allan is a member of the American Educational Research Association and has served as a consultant for the National Center for Educational Statistics.

Susan P. Bliss, Columbia, is an instructor in the College of Education, Special Education Department, University of Missouri-Columbia. She has served on the board of the Missouri Head Injury Association and as Mid-Missouri Chapter presidents. Other professional memberships include Missouri Association for Children with Learning Disabilities, Council for Exceptional Children and American Society of Training and Development and the Missouri Chapter. She is the parent of a daughter who suffered a head injury in 1975. She was appointed April 1989.

Michael H. Brooke, M.D., St. Louis, served as Medical Director of the Irene Walter Johnson Institute of Rehabilitation, Washington University School of Medicine, and Professor of Neurology and Professor of Preventative Medicine, Washington University. He belongs to the American Neurological Association and American Academy of Neurology (Fellow). Dr. Brooke resigned September 1988.

Caroline A. Castillo, Kansas City, is employed at Counseling Consultants of Clinton. She received a Bachelor of Arts in Education in psychology in 1985 and a Master of Arts in counseling in 1989. She received a closed head injury in 1980.

Donald M. Claycomb, Ph.D., Jefferson City, is the Executive Director of the State Council on Vocational Education. He is a member of the Committee on Liaison to the National Councils on Vocational Education, National Association of State Councils on Vocational Education.

Senator Edwin L. Dirck, St. Ann, served as the first chairman of the council from 1985 to 1987. During the summer of 1984, he chaired a Joint Interim Committee on Head Injury which held a series of statewide public hearings. Following the hearings, he introduced and passed the mandatory seat belt law. He also sponsored and passed the legislation establishing and regulating trauma centers. He serves as chairman of the Senate Budget Control Committee, as vice chairman of the Senate Aging and Mental Health Committee and as chairman of the Legislative Research Committee. He also is a member of the Senate Insurance Committee and the Ways and Means Committee.

Ben H. Ernst, St. Louis, is the Director of the Rankin Technical Institute. He is past president of the Missouri Association of Private Career Schools and past president of the American Technical Educational Association. He serves as the Regional Representative of the American Technical Association; member of the American Vocational Association and is Financial Secretary to the Board of Trustees of Rankin Technical Institute.

R. Dale Findlay, Jefferson City, is the director of the Missouri Safety Council. He is past vice president of the Association of the Association of Safety Council Executives and is serving on the Governor's DWI Advisory Council. He is also a member of the Missouri Advisory Council on Alcohol and Drug Abuse.

Robert G. Frank, Ph.D, Columbia, is Associate Professor and Vice Chairman, Department of Physical Medicine and Rehabilitation, School of Medicine, University Hospital and Clinics, University of Missouri. Dr. Frank is a member of the Mid-Missouri Psychology Consortium Coordinating Committee.

Donald L. Gann, Ed.D., Assistant Commissioner (head) of the Division of Vocational Rehabilitation, Department of Elementary and Secondary Education. He is a member of the National Rehabilitation Association and the Council of State Administrators of Vocational Rehabilitation. He represented the Department of Elementary and Secondary Education on the Joint Interim Committee on Head Injury.

Charles H. Goforth, Springfield, is President and Administrator of UpJohn Health Care Services serving sixteen counties in Southwest Missouri. He is a member of the Missouri Advisory Council for Home Health Care.

L. Dennis Humphrey, Ed.D., Springfield, is a professor in the Department of Biomedical Sciences, Southwest Missouri State University. He is secretary of the Board of Directors, Springfield Coalition for Disability Rights. He is also a member of the Handicapped Advisory Committee, Mayor's Commission on Human Rights; of the Advisory Council of the Wolfner Memorial Library; and past member of the Missouri Governor's Committee on Employment of the Handicapped.

Gerald J. Kampeter, Jefferson City, is the parent of a daughter with a head injury. He has worked for the Missouri Highway and Transportation Commission for over 35 years. He is active in the Highway and Transportation Employees Association and the Travelers Protective Association of America.

Nancy Koenig, Florissant, is the parent of a son who suffered a head injury. She has served as president of the St. Louis Bi-State Chapter of the Missouri Head Injury Association and as vice president of Operation of the Association. She is a retired elementary school music teacher.

Jane Y. Kruse, Jefferson City, is the director of the Division of Medical Services, Department of Social Services. The division has responsibility for administration of the state Title (Medicaid) program. She is an attorney and a member of the Missouri Bar, Missouri Health Coordinating Council and the Alzheimer's Disease Task Force.

Donald E. McGowan, Wentzville, is safety director, BOC Group-General Motors Corporation, Wentzville Assembly Center. He is chairman of the Board of Directors of the Safety Council of Greater St. Louis and is past president of the board. He also served as a member of the Board of Directors of the Missouri Safety Council from 1980 to 1984.

Representative Carole Roper Park, Sugar Creek, chairs the House Appropriations Committee on Health and Mental Health. She also serves on the House Budget Committee; Energy and Environment Committee; House Tourism, Recreational and Cultural Affairs Committee; and the House Ways and Means Committee. She is the recipient of various awards including the 1984 Distinguished Health Legislative Award by the Osteopathic

Association. She is active in many organizations advocating for persons with developmental disabilities and persons with mental illness. Representative Park was appointed to the council by the Speaker of the House in March 1989.

Representative Marvin E. Proffer, Jackson, co-chaired the Joint Interim Committee on Head Injury. He served as chairman of the House Budget Committee and the Legislative Research Committee. He co-sponsored the legislation establishing the head and spinal cord injury registry and the Missouri Head Injury Advisory Council. He also sponsored legislation during the 1988 session which contained a provision for repealing the sunset provision of the seat belt law. Representative Proffer retired from the Missouri General Assembly at the end of his term and, thus, resigned from the council January 1988.

C. Keith Schafer, Ed.D., Holts Summit, is the director of the Missouri Department of Mental Health. The department operates three service divisions: Division of Alcohol and Drug Abuse, Division of Mental Retardation and Developmental Disabilities, and the Division of Comprehensive Psychiatric Services. Dr. Schafer was appointed to the council in April 1989.

Thomas M. Sullivan, Jefferson City, is deputy director of the Department of Economic Development. He previously served as the director of the Missouri Senate Research and as the director of the Missouri Senate Appropriations Staff. Mr. Sullivan resigned April 1989 and was replaced by Charles (Chuck) Renn.

Nathan B. Walker, Jefferson City, is the director of the Division of Highway Safety, Department of Public Safety. He serves as Missouri's Governor's Representative to Highway Safety and is a member of the Governor's Council on DWI. He served two terms as state representative from 1980 to 1984. In 1982, he was elected as the Minority Whip of the House of Representatives.

C. Keith Whittaker, M.D., Kansas City, is a neurosurgeon at St. Luke's Hospital, Kansas City. He is a member of the American Medical Association, Missouri State Medical Society and American College of Surgeons. He is president of the Missouri Neurosurgical Society.

Senator Harry Wiggins, Kansas City, served as a member of the Joint Interim Committee on Head injury in 1984. He chairs the Senate Ways and Means Committee and serves as vice chairman of the Senate Judiciary and Public Health and Welfare Committees. He serves also on the Senate Appropriations Committee, Interstate Cooperation and Rules, Joint Rules & Resolutions Committees. He handled the house bill in the Senate which created the head and spinal cord injury registry. He was the sponsor of the senate version.

Lorna M. Wilson, R.N., C., MSPH, Jefferson City, is the director of the Division of Local Health and Institutional Services, Department of Health. The division operates the Missouri Rehabilitation Center which has a head injury unit. She is a member of the Missouri Nurses Association, American Nurses Association, Missouri Public Health Association and the Task Force for Local Health for State Board of Health.

About the Staff

Susan L. Vaughn, M.Ed, Jefferson City, is the director of the Missouri Head Injury Advisory Council. She has over thirteen years of experience in state government and in the field of disabilities. She has previously been employed as a speech therapist at B.W. Sheperd State School for the Severely Handicapped, operated by the Missouri Department of Elementary and Secondary Education, as a regional coordinator of the Region IX Council on Developmental Disabilities, and as a program specialist (staff for by the Missouri Planning Council for Developmental Disabilities) and as the assistant to the director of the Department of Mental Health in Jefferson City. She represented the Department of Mental Health on the Joint Interim Committee on Head Injury.

Lois M. Lorenz, Jefferson City, is the secretary for the head injury program. She has worked in state government of over eight years having worked for the Department of Mental Health both in the Division of Alcohol and Drug Abuse and for the department director's office. Prior to the department, she worked for the Office of Administration, Division of Personnel.

State Services for Missourians with Head Injury: *A Chronology of Events*

1983

- ◆ The Missouri Department of Elementary and Secondary Education, Division of Vocational Rehabilitation, assigned a vocational counselor in each district office with the responsibility of working with clients with head injury and began providing in-service training on head injury for DVR counselors.

1984

- ◆ The Missouri General Assembly passed Senate Concurrent Resolution 12 creating a Joint Interim Committee on Head Injury during the 1984 legislative session.
- ◆ The Joint Interim Committee held statewide hearing with the assistance of the Missouri Head Injury Association.

1985

- ◆ The Joint Interim Committee on Head Injury issued a "Report and Recommendations" outlining the extent and problems associated with head injury, lack of services, and recommendations for addressing the problems, including recommendations for prevention strategies.
- ◆ The Missouri General Assembly passed a mandatory seat belt law, with a sunset provision, which was signed by the governor.
- ◆ Governor John Ashcroft created the Missouri Head Injury Advisory Council to plan and coordinate services by way of an Executive Order March 1985.
- ◆ The Missouri General Assembly appropriated funding (state) in an emergency bill for staff and expenses for the Missouri Head Injury Advisory Council, which was assigned to the Missouri Office of Administration, and funding for Fiscal Year 1986 (beginning July 1, 1985).
- ◆ The Missouri General Assembly passed legislation changing the name and mission of the Missouri Chest Hospital, operated by the Missouri Department of Health, to the Missouri Rehabilitation Center (Mt. Vernon).
- ◆ The Missouri General Assembly appropriated state funding to the Department of Health for contractual services for persons with head injury for Fiscal Year 1986.
- ◆ The Missouri Head Injury Advisory Council held its first meeting September 1985.
- ◆ The Missouri Head Injury Advisory Council co-sponsored with the University of Missouri

School of Medicine the conference "Head and Spine Injuries and the Epidemic of Trauma in Missouri," October 1985.

- ◆ The Department of Health and the Office of Administration, Division of Purchasing, issued Request for Proposals for head injury services with assistance from the Missouri Head Injury Advisory Council.
- ◆ The Missouri Department of Elementary and Secondary Education, Division of Special Education, assigned central office staff to work with school districts which have students with head injury.

1986

- ◆ The Department of Health awarded contracts to seven agencies throughout the state for a variety of head injury services.
- ◆ The Missouri Head Injury Advisory Council defined "head injury" and head injury services and issued the report, *Proposed Service Delivery System for Rehabilitation of Missourians with Head Injury: Service and Program Definitions*.
- ◆ The Missouri General Assembly passed legislation to establish a head and spinal cord trauma registry and to establish the Missouri Head Injury Advisory Council statutorily.
- ◆ The Missouri Head Injury Advisory Council conducted a survey of Missourians with severe head injury served by mental health, home health and nursing home facilities and agencies and issued a report of its findings.
- ◆ The Missouri Head Injury Advisory Council published its first newsletter, *Quarterly*.
- ◆ The Missouri Head Injury Advisory Council published its first annual report for FY'86.
- ◆ The Missouri General Assembly appropriated staff to the Missouri Department of Mental Health, St. Louis State Hospital, for a head injury unit for patients with head injury and aggressive/severe behavior problems for Fiscal year 1987.
- ◆ The Missouri Head Injury Advisory Council held its first annual statewide conference on research, rehabilitation and service needs, "Head Injury: Meeting the Challenges". (Participants included state legislators, state agency personnel, other professionals and family members.)

1987

- ◆ The Missouri General Assembly passed legislation establishing a statewide trauma center system.
- ◆ The Department of Health appointed a committee to develop the form for the head and spinal

cord injury register, trained appropriate hospital staff with regard to the completion of the form, and implemented the registry July 1, 1987.

- ◆ The Missouri General Assembly at the request of the Department of Health transferred the appropriation for contractual services to the Office of Administration, Division of General Services, and contracts were extended by the division.
- ◆ The Missouri Department of Elementary and Secondary Education published a manual, *Developing Individual Education Plans for Students Who Have Suffered Traumatic Head Injury: Procedural Guidelines* to assist school districts with students with head injury.
- ◆ The Missouri General Assembly passed legislation allowing sheltered workshops to receive a portion of the state subsidy for those handicapped workers, including persons with head injury, who are unable to work a six hour day.
- ◆ The Missouri Attorney General issued an Opinion stating that a person with a head injury would meet the definition of "handicapped" in Section 205.968 RSMo, and, thus, a county mill tax for programs for persons with developmental disabilities or other handicaps could be used to fund programs for persons with head injuries.
- ◆ The Missouri Head Injury Advisory Council sponsored its second annual conference, "Head Injury: Focus on the Future".
- ◆ The Missouri Head Injury Advisory Council included in its FY'87 Annual Report a state plan for developing a statewide service delivery system for persons with head injury and their families and developed one to five year goals and objectives for the council to undertake in order to obtain a service system.

1988

- ◆ The Missouri General Assembly passed legislation to expand the state Medicaid eligibility criteria and eligible services to include comprehensive day services for post trauma patients.
- ◆ The Missouri Head Injury Advisory Council recommended and developed a statewide phone survey which was conducted by the University of Missouri-Columbia, School of Journalism, Bureau of Media Research, to determine the awareness and knowledge of the public with regard to head injury and the prevalence of head injury.
- ◆ The Department of Mental Health, Division of Mental Retardation and Developmental Disabilities received approval for a Home and Community Based Medicaid Waiver to allow federal Medicaid reimbursement for certain services for eligible clients which include those division clients or potential division clients with head injury.
- ◆ The Missouri General Assembly passed legislation which repealed the sunset provision of the seat belt legislation.

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- ◆ The Missouri General Assembly passed legislation requiring persons under 18 to wear a helmet while riding an all-terrain vehicle (ATV); requiring persons under 16 to be supervised by an adult while driving an ATV; prohibiting ATVs on public roads and highways except under certain conditions; and prohibiting passengers on an ATV.
 - ◆ The Office of Administration, Division of General Services, and the Missouri Head Injury Advisory Council co-sponsored a public hearing to obtain input for service priorities for head injury contracts.
 - ◆ The Missouri Head Injury Advisory Council sponsored its third annual statewide conference, "Head Injury: From Injury to Independence", attended by approximately 250 people.
 - ◆ The Missouri Head Injury Advisory Council chairman established a Task Force on Service Delivery System Recommendations to study the need for a division of head injury within state government.
 - ◆ The St. Louis State Hospital operated by the Department of Mental Health, and the Missouri Rehabilitation Center, operated by the Department of Health, began the process of developing an inter-agency agreement regarding clients served by each facility, referrals, and coordination of services.
 - ◆ The Missouri General Assembly appropriated state funding for the first time to the Department of Health for purposes of expanding prevention programs modeled after the Missouri Head and Spinal Cord Injury Prevention Project conducted by the University of Missouri-Columbia.

1989

- ◆ The Department of Health received two contracts from the National Highway Traffic Safety Administration to link five data files to track patients from the scene of the accident to after hospital discharge and to study costs of injury. The department will link five computerized data files: Statewide Trafficway Accident Reporting System (STARS), Ambulance Reporting System, Head and Spinal Cord Injury Registry, Death Certificate, and Hospital Discharge. The STARS is administered by the State Highway Patrol and the other four are administered by the Department of Health, Division of Health Resources. The second contract calls for researching costs associated with injuries (pre-hospital, hospital, and after discharge).
- ◆ The Missouri Head Injury Advisory Council sponsored its fourth annual conference, "Building Service Delivery Systems for the 90's."
- ◆ Legislation was introduced for the first time calling for the establishment of a division of head injury and rehabilitation in the Department of Health. The bill passed the Senate and fell short by three votes of passing the House of Representatives.

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- ◆ The Missouri General Assembly appropriated state funding to the Missouri Rehabilitation Center for four beds for persons with head injury with severe behavior problems.
 - ◆ The Missouri General Assembly appropriated state funding to the Office of Administration, Division of General Services for long-term support services to enable persons with head injury to participate in the federal supported work program administered by the Missouri Division of Vocational Rehabilitation.
 - ◆ The Centers for Disease Control (CDC) approved a three year grant to the Department of Health for the department to establish a state injury control program.
 - ◆ The Missouri Head Injury Advisory Council, the Division of Vocational Rehabilitation, and the University of Missouri-Columbia sponsored an in-service training workshop on vocational and supported work issues for community providers.
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